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LEX FRIEDEN: Good morning, ladies and gentlemen, I'm Lex Frieden I'm chairperson of the national council on disability, and I'm very pleased to be here to welcome you all to this important meeting today and tomorrow. The issue of aging and disability is not one that is far out of the purview of those of us with disabilities who are becoming older. And I guarantee you it is not far out of the purview of those older persons who are quite naturally becoming disabled. It is a part of life that we all hope we can live long enough to appreciate and enjoy. And I think the key to that statement is appreciate and enjoy because it wasn't too long ago that when people thought about becoming disabled, they braced that subject with fear. And still today, many people who think about becoming disabled, whether it be it by accident, injury and illness, or by the natural effects of aging, many people today are apprehensive about the impact of aging on their lives. People think about living in nursing homes and being cared for by persons who don't have an interest in their well-being. They think about having to manage money that is dwindling away as a result of inflation, and other economic factors, and they are concerned about their children, who they can no longer provide for and who are occupied themselves perhaps without time and energy to care for them.

So aging and disability are two subjects that have a natural nexus here and it is so important for us to address them. But now, unlike before, we can look forward to aging with disability in a positive context, and that is due in large part to the efforts that many of you in this room have made in the past two decades, and I'm pleased to know many of you and look forward to knowing those of you whom I don't know, but I can assure you speaking as a person who has lived with disability now for more than 3 decades, life is getting better. It's getting better. And I guarantee you that if we work together to ensure the full implementation of the Americans with Disabilities Act, life will continue to improve. One Giant leap was made not too long ago by the US Supreme Court and people ask what has the Supreme Court done to hurt ADA, and I say what has the Supreme Court done to help ADA, and if you all understand the implications of the OLMSTED decision by the Supreme Court, you know the impact of that decision goes well beyond some of the technical decisions that have been made about the definition of disability in the ADA. The OLMSTED decision is making a see change among public agencies as it effects the people with lives of disabilities, who at one point only had to look forward to the nursing home care if they were disabled and indigent, and now people under those conditions are being able to look towards life in the community at a higher quality of life, and more independence in terms of managing and deciding how to manage their lives. Again, this wouldn't have happened without your commitment and it wouldn't have happened without the commitment of the speaker who I'm so pleased to introduce to you today. Dorcas Hardy was sworn in by then vice president, George bush, in 1986 as the commissioner of the US Social Security Administration. At that time, I had the pleasure of serving as executive director of the national council on disability, and Ms. Hardy had the courtesy and the presence to come to my office and meet me, and talk about disability in the context of the Social Security program. And she was one of the first public servants whom I know that understood the consequences of disability in the Social Security program. She understood that there are disincentives built into our programs that prevent people with disabilities from being fully engaged in life. She is the one who pointed out to the council that we needed to recommend in our report called for independence, the removal of disincentives from the Social Security program, so that people who had become disabled but were still able to work could do so without risking all of the important benefits that they acquired as a result of their disability. And since then, she has continued to work as assistant secretary at HHS. Who is head of the VA's program to revitalize rehabilitation programs for people with disabilities, and in many other capacities she is hooked to television shows, written articles, and served as a voluntary advisor to many not for profit organizations as well, I might add as a paid advisor, and I hope you were well paid.

### (Laughter.)

A service to banking institution financial institutions and for profit companies that are trying to design programs for the future and to take into account the natural effects of aging. And here we are today with the opportunity for me to introduce to you, the chairperson of the White House Conference on Aging policy committee, Dorcas Hardy, thank you very much.

## (Applause.)

DORCAS HARDY: Thank you LEX. It has been almost 20 years since that meeting, and we have made some progress, but we look to you all to make even more. I'm delighted to be here. And to -- it is really an honor to talk with you here at this White House Conference on Aging 2005, what we call mini conference on disability and aging.

You have been organized by an incredible planning committee that is made up of advocacy organizations, of consumer advocates, America deem me a, let's see who have I left out, other nonprofit organizations. The private sector, insurers, everyone we can think of who really should be in this room and I congratulate the planners for having to put together all of this, especially with American's health insurance plans, and Margaret Campbell who is at NIDRR over at the Department of Education, you have done a phenomenal job. This is the group that can make things happen so I'm glad to be here. I want to introduce a few other folks to you who have something to do with the White House Conference on Aging which you know is coming to Washington December 11, through 14th of we think it is -- I think it should be 2009 but it will be 2005. And we have here today deputy assistant secretary for policy planning over at the VA Mike MCCLENDAN who has just been appointed by secretary Levitt, we also have Bob on the policy committee who ran an incredible conference in 1995, and Carolyn gray is here who is a partner with

Barnes and thornburg here in town and chairman of the disability practice group at the Washington firm and an architect of ADA, as many of you know her, and I believe we are going to be joined sometime toot by Larry POLIFKA who is from the great State of Florida and is very involved in Tampa at the university in disability and aging issues. So we are well represented. We are pleased to be part of this, and we are very much looking forward to what you have to tell us, I think the next two days present all of you a real opportunity to get it right. And to really come up with some real positive resolutions that can be looked up by the policy committee of the White House conference, and we can move forward and take those recommendations and present them to the delegates at the conference. I think as LEX indicated, we haven't quite gotten it right yet, because many federally sponsored and funded programs are not quite on the right track. They are not particularly aligned in many cases with national disability policy as we would like to see, and that appears to still be mostly correct with regard to Social

Security definition of disability, which many of us -- most of us will agree is still at odds with the desire of many disabled persons who want to work but who still need some financial or medical assistance. And that balance we still haven't found yet. And there's similar conflicts, if you will, that exist at the Veterans Administration in their adjudication process so we recently learned that there is 40 to 50, maybe 59 definitions of disability, just within the federal sector, let alone the private sector, and none or almost none has to do with function. And so does that really make all of us think that we are indeed in the 21st century. Where society, and as that society and persons who are part of a disability policy community, all of us need to recognize and advocate that programs can be much better if they are addressing what people can do rather than what they can't do. And that with many accommodations that exist today it is possible to offer many individuals with disabilities a very satisfying job, so in that regard we need to really figure out how to make ADA a complete, I know you are participating next week in all sorts of celebrations. That is very positive. We have taken very positive steps forward which is not quite totally there. So we have lots of issues to tackle at this time and in the future. We need to be looking at tasks that are not particularly easy, and this is one of them. And the White House Conference on Aging has designated disability "as a broad issue that effects all pieces of the conference agenda." And that's why the policy committee looks forward to hearing your remarks and your ideas and your resolutions and also your implementation strategies as you look to the next couple of days. So from that mini conference and someone had asked me what my expectations were and I think I speak on behalf of the policy committee that we would like to see a limited number, a very realistic doable recommendations that the policy committee can present to the delegates. And these conversations, these resolutions, I think can be a cat take lift to help all of us to help our nation, to help our leaders identify very concrete policy steps to address the economic, the social, the environmental, and the personal challenges that disabilities can presentfor individuals, for e-mail employers, for communities, and those who are aging and their families. You recall that the purpose of the conference which is held every 10 years, is to make recommendations to the president of the Congress, but the policy committee has thought there is more in this world than just the president and the Congress. There is individuals, there is local governments, there is state governments. There is communities, there is private sector, there's folks who are really interested in all of these issues. So it is just not the president, and the Congress, and the federal deal. It is all of us together. And that is is the kind of ideas that we do want to see. The -- as we look to this years and beyond, we have got to also take into account the aging not just all of us here, but the ones who are coming through that great baby boom. million of us as baby boomers will soon join the ranks of an older US population, at the stroke of midnight on January 1, 2006, which is less than a month after the conference, baby boomers will begin to turn 60, and will continue to do so every 7.7 seconds.

### (Laughter.)

DORCAS HARDY: So I want each of you to think when your 7.7 seconds your turn comes up. It is an overwhelming statistic and when you think about the number of older people that we can anticipate in the United States in the next 10 years it is mind boggling. So by the middle of the century there about be a quarter million people 100 and over, which is about 4 times the current number that we have, and the number of people age 65 and up, will increase by nearly 150 percent. What is even more dramatic is the 54 million persons of all ages who have disabilities in the United States, the majority of whom are working age, and are also aging, as LEX talked about, and that they will also require -- may require, health, social services, personal services, and they want to continue to be engaged productively to the best of their ability. According to the 200 census, the more than 33 million persons over 65, which is almost 19 percent of our population, have a disability, and many people with disabilities, without regard to age do not characterize themselves as having any kind of disability. Increasing deafness, limited vision, gait difficulties, all of these words that we all know, that the answer is not necessarily "disabled" it is about impairments that we all have, that persons, all of us have as functional impairments, we know because disability rises with age and because people are living longer with disabilities, that we might have led many of those might have led to deaths many years ago or only several years ago. The numbers will continue to rise as the baby boomers age. You are going to hear a lot more about public and private roles this that area, and how they are expected to increase. In fact, Dr. Ron Leopold is here from MetLife and I'm sure he will be talking about the workplace disability accommodations number of people, and how that is increasing dramatically. These facts have been part of our conversations, and those held throughout the country, with regard to the White House Conference on Aging. And we have looked the policy committee, I think you have seen most of you have seen you are agenda, is focused on six broad areas, and we are -- where disability goes through all of them. Planning along the life span, heat and long-term living, the workplace of the future, civic engagement, our community, and the marketplace. And that agenda is serving as the basis for those resolutions that come into the conference, and I expect that disability will go throughout those. We have had listening sessions. We have had solutions forums, we have had mini conferences like today's and we are getting to the end of that input process, and we have touched, or more than 100,000 persons have come in and touched the White House Conference on Aging already. And it is through these events that we have been trying to identify the most important issues, the things that are of greatest concern, and in this case, that address both the field of aging, and disability. As we look to that, I think there is going to be a lot of interest in what you are doing today and tomorrow. We know this if Landmark ADA which has since we said its anniversary next week and the president's new freedom initiative have helped to open more doors for persons with disabilities, and despite governmental leadership we also know too well that there is many challenges that continue to exist. So we look at some of these examples. We have got questions about short and long-term home and community based support services. We have got disability definition questions that we need to address. And we need to be looking at the kinds of definitions we should have in the future. We have issues of income, education, ethnicity and even regional and geographic locations that have to do with disability. I understand that of the 2000 census that also found that 2 out of 5 persons with a disability lived the south. Well, only 1 of every 5 persons lived in each of the other 3 regions of the United States. Why? I don't know. I'm not sure any of us here know. It is just that is one of the facts, and how do we perhaps have different kinds of issues, different kinds of communication with different communities throughout the country. We also have an aging veteran population not to slice and DICE pieces of the population, but that is something that is of great concern. We are seeing a reduction obviously in the World War II and the Korean war Veterans but also seeing new Veterans coming in and we are seeing a significant growth in the veteran's disability population, and so we have the older, we have the living longer, and we have the many cases the need for community services for those individuals. So how do we learn something from them? There have been a lot of advances in technologies. One -- this group is involved I believe in the 2000 White House technology exhibits and conference. And those are very important, and they will enable us to live better, and in many cases longer. But how do we harness technology for everybody? How do we match the right technology with the needs of the individual? So before you go into your sessions I would just like to comment at my closing comment here about envisioning the disability and the aging community in America over the next 10 years and beyond. Our community is ready for what this vision will mean in terms of our economic situation, employment situations, and possibly social support for those with disabilities. We have heard about livable communities. Are they just livable for some and not for others? How do we make that Browder? What do we think about minimizing barriers and decreasing fragmentation of service delivery. We all live in these as we said in the social service areas the SILOS how do we pull that together and serve people that serves people across the continuum if that is what they need and want. What about the individuals who may need support of family or paid caregiver. We know from our listening sessions as well, that older persons with disabilities may also want to work, continue to work, and remain in the workforce. What do we expect of employers? What do we expect of the employees. How do we mesh that, and how do we ensure that there are employment opportunities for everybody? How can we get some assistance with regard to public relations, marketing, if you will, to promote healthy lifestyles throughout our country as we prepare for older persons in general, older disabled persons, everybody who is coming through that pipe. How do we look ahead and say that we also many of us will want to volunteer more in the future, civic engagement participate in our communities, be of assistance, what kind of opportunities are those for persons -- will there be for persons who have disabilities? You are extremely a prestigious group. You come from around the country and you are some of the best and brightest minds in your fields and you have been involved in this area for a long time as many of us have. Some of you are pioneers. Some of you are LUMINARIESs and your efforts have shaped the conversations for today, and I specifically point that one of the briefs that Dr. Stapleton handed to me on disability policy and there is a lot of good ideas in this room, so I ask you to take this opportunity, think about the future. I ask you to be fiscally responsible, do some outside the box thinking. Think about what is really right and modern in the 21st century. Think about how we need to pay for things or not pay for things. Think about things beyond the Federal Government, and consider that the White House Conference on Aging can be a PULPIT for some of the ideas. Remember, it is not just disability and aging. It is a very broad based conference, and how do we become and what is your recommendations for becoming that BULLY, PULPIT. Be positive and don't be afraid of change, we have all been through it. We have made it through change, change is not so bad though it is scary, and there is really some bright ideas out there. This is anopportunity and I look forward to your best and brightest ideas, and receiving them, and I have confidence that you will come up with some very bright solutions, thanks a lot.

(Applause.)

MARGARET GIANNINI: Good morning. Oh, you are brighter than that, good morning. Hi, I'm Dr. Margaret.

MARGARET GIANNINI: , I have -- I'm now the director of the office on disabilities at HHS, and I have been in this field for longer than I want to admit. And with that, I really want to thank the planners, the chair of this mini conference, and his co-chair, Margaret Campbell, and the other hard working members of the organizing committee who have helped move this ground breaking, really ground breaking conference from concept to reality. You know, many times when we plan conferences, and we talk about aging, we leave out an important segment that LEX and DORCAS enunciated, disability, and so this is a very significant moment for all of us. I'm also pleased to see so many of you here that I have known for a long time. I have known for a considerable amount of time, and I have known more recently, and it is wonderful to see your enthusiasm and your presence here to support what we are trying to do. I also want to thank the rest of you that I don't know who have come from within, and outside of

Washington Beltway to be here, and to participate, and I want to emphasize that word participate. That is what this meeting is all about. There is a wonderful ETHIOPIAN proverb that says when spider webs unite they can tie up a LION and it is just that kind of coming together that this conference is all about. Individually, we are each one. Together, we are advocates for persons with disabilities, advocates for older persons, industry academia, and government, and this will become more than the sum of our parts. Together, we can make recommendations to the White House Conference on Aging as you have heard that can help make a difference. Not only today, but for a decade of tomorrows for older adults with or without disabilities. And that is why your

active participation, not just your presence is so very important. I have a personal interest in this topic of this conference, as well as a professional interest. Between my work as a health care professional involved in disability, clinical care, research, policy, administration, and all of the rest for over more than a half of a century, I guess you can see by my white hair why I have a particular personal interest.

## (Laughter.)

MARGARET GIANNINI: Over the years, I have seen the truth and the idea that the best way to predict the future is to create it. Over the century, thanks to the advances in public health like antibiotics vaccines and improved sanitization, life expectancy in the last 100 years has nearly doubled, as you heard, people are both living longer, and generally more health fully, that is what creating the future by taking action today is about, as a health care professional, I have witnessed, and in some ways even helped achieve advances in medicine, rehabilitation, research, development and technology, that would appear to be miracles in a very earlier day. We live in an age which smart homes enable older adults and persons with disabilities to live in comfort of their own homes, surrounded by friends, and family. That is what creating the future by taking action today means. We live in an age in which it is possible for persons with disabilities to enter the workforce and remain, even though we don't think it is enough. That's because by law, the Federal Government requires accommodations be made to facilitate persons with disabilities to achieve their full potential in the workforce. And we are predicting the future by creating it. We live in an age in which our Federal Government in partnership with state and local governments, the medical community, America deem me a and private industry are working together to tear down the barriers of persons with disabilities. Again, we are predicting the future by creating it. And we live in an age in which the president recognizes the inherent value of every person in this great country, whether young, or old, rich or poor, minorities or ethnics, disabled, or nondisabled. That's why President Bush launched his new freedom initiative, challenging the antiquated notion that persons with disabilities fair better in nursing homes than in their own homes. And without question, the new freedom initiative is predicting a new future for millions of persons with disabilities by creating it today. I believe so strongly in the new freedom initiative, that I answered President Bush's call to help coordinate HHS HHS many programs and iniatives focussed on disability, and my job at HHS includes helping to bring the vision of the president's new freedom initiative from words to reality in the lives of persons with disabilities, their families and their communities. And I hope we are achieving some of that. It is a vision that recognizes human dignity, individual worth, and the role each person can play in the life of the community. For some of you that are not familiar with the domains of the freedom initiative I will particular them off quickly. Integrate Americans with disabilities into the workforce, increase access to assistive technology and universally designed technology, expand educational opportunities, promote safe, decent housing, and whole ownership. Expand options in transportation, and promote full access to integrated community life. And critically, my work at HHS, I felt we should add another domain of critical importance and that is health, after all, without good health, the other goals of the new freedom initiative, really become meaningless because it is more difficult for individuals with disabilities to achieve without good health. Taken together, these goals dove tail nicely with the work being done at this conference in the next two days. I'm encouraged at the concepts of aging and disability that have brought together for discussion at one time in one place and the dialogue being in sync with each other. Both aging and disabilities are terms that res son nature for all of us, but all too often, they are not mentioned in the same breath, or the same sentence. That's even though we know that everyone is likely to have a disability at some time in his or her life, and I'm going to repeat what Greg Vanderheiden dear hide said to me this morning, he said that he heard a quote that everyone will have a disability sometime in their lives if they don't die first.

### (Laughter.)

MARGARET GIANNINI: That's even though we know that aging is an inevitable part of living, and that is even though 40 percent of persons 65 and up are living with a disability. That percentage jumps to around 70 percent among those in their 80s, and the fastest growing population in aging today is 85. And that population are women who have never married or had a significant other, or have had children. So women make your choice. Live longer, or have some fun.

### (Laughter.)

MARGARET GIANNINI: By Lynning these two issues, disability and aging, we are helping to realize President Bush's goal of lives of dignity engagement and community involvement. And the central role of health in both aging and disabilities is underly able. And also, work is, without good health, and those with disabilities work is less possible, social engagement and productivity are diminished, economic security is less likely and a sense of community can be lost. Let me provide you with a few quick definitions to set some groundwork as we get underway. Disability is not an illness. Just as health and illness exist among a continuum, so too does disability. The general public frequently equates disability and aging with the loss of ability, as you all know, NIDRR is accurate. Now, let me suggest a few challenges for our discussion about health illness and disability that can help inform the work that will follow. We are challenged to promote a culture of health promotion, to reduce the risks of disability, as we age, to reduce the risks of secondary conditions for persons with disabilities as they age. We are challenged to promote health care workforce knowledgeable and able to serve the individualized health needs of older adults and persons with disabilities. We are challenged to Foster the availability of a full range of all appropriate accessible and individualized held care and array of community based services to promote independent living, and we are challenged to identify and advance best practices in health care that result in full engaged and health I didn't lives for older individuals, after all, the concept underlying President Bush's new freedom initiative, is a concept that res son natures for everyone a value contributing, and healthful life in the community. This opening panel, and the panels that follow, are designed to stimulate creative thinking about aging and disabilities. That is today's work. So I encourage you to engage, and to get involved both in this panel, and in the work over the

course of this day, with SEPERB preparation. And I'm convinced if we do that, the recommendations that we will develop and agree upon tomorrow, can help make all of the difference. I'm convinced further, that our SUPERB work today and tomorrow can make a real difference in policy and program directions for aging and disability over the coming decade. Sir William OSTER once remarked that the best preparation for tomorrow is to do today's work SUPERBLY well, so with that, let's get underway and let's roll. Thank you.

## (Applause.)

Thank you and now to our speakers. Our first speaker, unfortunately, is not Dr. Administer intrator of the -- he was summoned to Capitol Hill today unexpectedly and when the house or senate calls as many of you know it is an offer that one does not refuse. However, we are most fortunate to have with us, Miss Jacqueline garner who serves as the acting deputy director of CMS center for state Medicaid operations. As you probably know, Medicaid is a program of particular importance for persons with disability of all ages, and consistent with the new freedom initiative, has been placing renewed emphasis on community based services instead of institutional care. The interconnections between the Medicare, and Medicaid programs, have never been greater particularly as theMedicare modernization act moves forward. Let me tell you a bit about Jackie garner, Jackie first joined the centers for CMS in May of 23 2003, as the Chicago regional administrator. She brings as rare combination of federal, state, and community based knowledge to her role at CMS. Her more than 2 decades of experience in HHS HHS includes extensive experience in the nonfor profit leadership health care program and policy and advocacy. Jackie also served as a member of the governor's cabinet in Illinois where she directed the Illinois department of public aid, the state Medicaid, and CHIP agency, as director, she oversaw the development and implementation of one of the first State Farm say waiver programs and also focused on program integrity and fiscal accountability improving the agency physician scale reputation, I'm so pleased will you welcome with me Jackie, particularly on this very short notice, thank you.

# (Applause.)

JACKIE GARNER: Thank you Dr. MARGARET GIANNINI: , I want to thank you Dorcas Hardy for allowing me to speak today and I spend my regards from Dr. MCCLELLAN. He did want to be here, he personally called me yesterday and asked me to step in. I'm sure he would want to be here on any day but especially on a day when his other choice was testifying in front of the Ways & Means Committee, I'm sure he would like to be here. He did tell me that if he is released, he hopes very much to be able to stop by at lunch. So I'm hoping that he will have that opportunity. What Dr. MCCLELLAN asked me to speak about, is some of the good progress in rebalancing the health care system in favor of individualized personalized community based care for community with disabilities, I would also like to talk with you today about how we might work together so that the people that you work with, can take full advantage of the newMedicare prescription drug benefit. This is a very special and a very critical time for CMS. We really are experiencing a sea change in how we administer our programs and we are bringing them into the 21st century. And there are two major programs that should get credit. As has already been mentioned and I'm going to talk about it a little bit more, is the president's new freedom initiative, and secondly, the Medicare modernization act or as we refer to it, EMMA. To understand that this sea change is underway, just remember that Medicare and Medicaid turned 40 this month, and when these two programs began 40 years ago, cutting edge medicine was institutionally biased, and provider driver. The setting for long-term support was institutional care. Our programs needed to change with the times. One of our top priorities at CMS is to achieve President Bush's new freedom initiative. Which aims to secure for everyone, optimal care for individual needs. In health care, as Dr. MCCLELLAN knows firsthand, one size does not fit all, and that is why CMS is working hard through the new freedom initiative to craft a Medicaid program that supports community based care. Now, these programs include independence plus, which is our premiere self-direction program which allows individuals and their families to decide how best to plan, obtain, and keep services going in the community. It is based on lessons learned from states on the front line of consumer self-direction. We also have our home and community based waivers, we sometimes refer to them as section 1915 C, being good beaucrats, which have been important in confronting the rising demand for long-term care services, and by integrating the elements of independence plus, a key approach to encourage system rerebalancing, our home and community based care demonstrations, which support RESPIT services to CAREGIVERS of adults with disabilities, children with severe disabilities, and community based services for children in psychiatric residential treatment facilities. We are also working on choice systems change and other grants to support alternatives to instutionalization, to help people with disabilities or long-term illnesses live in their homes, and participate fully in community life. Another one of our iniatives, is part of the president's 2006 budget. It is a 1.75 billion dollar proposal over five years, that builds on lessons learned from the real choice system change grants, and underwrites state efforts to retool their community support systems to offer citizens an effective balance of both community and institutional services and enable money to follow the person across long-term settings and providers.

We are also working on partnerships with other federal agencies, such as HUD, the VA, and the Department of Labor along with SAMSA, to, among other things improve our outreach to the homeless. And in our independence and employment iniatives, such as the Medicaid restructure grant program, we are doing similar approaches. Our efforts to expand choice, and control for individuals extend beyond the new freedom initiative, and for example, just last month, CMS approved Vermont's section 1115 research waiver, and this waiver is really quite unique. It sets up a triage system to evaluate settings for people who might benefit from home or community based services. Vermont's plan covers about 4500 Medicaid recipients 65 and older, and physically disabled adults to prevent or delay the need for institutional care. We are also continuing to work with our PASA agencies or our preadmission screening and review regulation, which among other things supports community based mental

health services by helping prevent an appropriate admission to Medicaid nursing facilities of individuals with serious mental illness, which is something that I worked quite a bit on in Illinois.

Helping to implement OLMSTED through one-time Medicaid payments to help patients move back or stay in the community remains a priority. Now, institutional care is right for some, but it ought to be one of a range of options, with more than two decades now of experience behind us, with the OLMSTEAD decision, and with overwhelming evidence, we just can't afford to wait any more from the standpoint of people with a disability. There should be no misunderstanding, Medicaid's investment in the future is a simple -- is essential, and we will not compromise patient care. But we are committed to Medicaid's individual self-direction and empowerment, and we are putting our money with our mouth is. But a big part of investing in Medicaid's future is making sure that American's most vulnerable patients, who are typically beneficiaries of both Medicaid, and Medicare, we refer to them as those that are dually eligible for both programs. We want to make sure that they have access to the care they need, and a critical part of that is prescription drug coverage, which is what we are achieving through the MMA.

This new drug benefit will provide substantial help to low income people withMedicare, as well as otherMedicare covered individuals when it takes effect next January 1, 2006, just about the time those people that Dorcas talked about, those of us in the baby boomer range start turning 60. They are also now going to get drugs through theMedicare program.

People with mental illness, cancer, or HIV AIDS will not be required to switch medications. Even when their drugs are not on the state's preferred drug list, we have streamlined the appeals process for any exceptions that arise. Now, theMedicare drug benefit is going to be available on schedule, but that requires CMS to make sure well before it is on line that people will be able to choose with confidence the plan that is right for them. It is helpful to think of covered individuals in terms of five main groups of people. The first group is people withMedicare, who currently have Medicaid drug coverage, those dually eligible. These folks will automatically receive comprehensive drug coverage fromMedicare. This group will get help signing up for aMedicare drug plan in the fall, however, if they fail to choose a planMedicare will automatically enroll them in a plan on January 1st, 2006 so they will not miss a day of coverage, and we are working in Medicaid very, very closely with our state partners and our community partners in the business community, and the provider community to make sure that this happens. The second group is individuals with limited incomes. We again are working very closely with our partners at the Social Security Administration to make sure that these people should sign up as soon as possible for the extra helpMedicare offers that will pay for 85 to 100 percent of their drug costs depending -- and that is going to depend ontheir income and financial resources. This group will also get help signing up for a drug plan in the fall. However, if they don't sign up on their own,Medicare will enroll them in a plan next year to make sure that they get comprehensive coverage.

The third group, is people who currently have retire rye drug coverage, and Medicare can help this group pay for drug coverage from their former employer or union, and the way that is going to happen, is if their retire rye drug coverage meets Medicare standards. This fall, retire rye benefit plans will let individuals know what decisions they need to make in January 2006.

The fourth group, is people with Medicare advantage, the Medicare advantage care program. These folks will get even more coverage through their Medicare advantage health plan,

and more information from the health plans will be available this fall about their coverage options.

And the fifth group, is other people withMedicare. And this group includes people with higher incomes, who also will need to make the decision aboutMedicare drug coverage and they too can safe money if they enroll on time by May 15th, 2006, with coverage that never runs out.

Now, there is a brochure out on the table that lays out all of the timelines and some basic questions, I encourage all of you to pick that up. Right now we are focusing on getting the word out to dual eligibles, individuals, again, who are eligible for bothMedicare and Medicaid, SSI recipients, and others who need help the most. The low income subsidy will pay for almost all of the low income persons prescription drug costs, approximately 95 percent. For most of them, the extra help means no premiums, no deductibles, no gap, no co-pays. Or co-pays of only a few dollars for all prescriptions. The Social Security Administration is sending out millions of low income subsidy applications now, that many below income people may not realize they are eligible for financial help, so we are asking everyone who gets the application to fill it out. Whether they think they might be eligible or not. We are saying when in doubt, fill it out. This application, and I imagine that we will hear more about in this morning, but this application has just four pages of questions. It doesn't require any applications. It has been field tested over and over again, and if someone just fills out a part of it, that person can send it in and Social Security will call them back to get the rest. I'm going to ask for your help today. You are the experts. You are involved in so many networks at the federal, state, and your community level, most importantly, we need to make sure that everyone that can men fit from the newMedicare part D, will benefit. We are right in the middle of a new nationwide outreach campaign called Medicare covers America. And we are educating Americans about the prescription drug benefit. And as you likely know, we are working closely with the HHS office on disability to develop specifically tailored information for the disability advocacy community. You know this population. You work on their behalf every day. And no one is more qualified or better equipped to reach out to people with Medicare and their CAREGIVERS. So here are the dates to remember. On October 1, Medicare will mail out materials including this year's Medicare handbook. Information is also available by calling 1800 Medicare, or by visiting our website atMedicare.gov. And on November 15, individuals can start to enroll. We are working hard to get the word out. We are also

working hard to establish community enrollment centers. We are working with our partners to make sure that one on one counseling is available to individuals. So that they will have assistance in enrolling.

Our resources include not only consumer oriented print materials but also as I mentioned earlier, materials on our website. We have a whole set of training materials for any of you who might like to get really involved, and participate in some community-based training, and those are available on DVDs. We are working with other partners such as the agency on aging, the national council on aging, our partners at AARP to provide as much help as we can. Other federal agencies that we are partnering with, this really is not about just HHS. This is about the Federal Government bringing all of its resources to BARE, to help get the word out and provide information so that beneficiaries can make a good choice. So we are working with federal agencies such as transportation, transportation, housing and urban development, agriculture, we are working state and local governments, today there is a big roll out in Chicago, the mayor has mobilized all of the health departments to get involved, we are working with employers, unions, doctors, pharmacists, CAREGIVERS and other senior organizations and we are targeting at the local level so that we can get to people withMedicare, their children who can also be of great help and CAREGIVERS. And I hope that CMS can count on you as partners to help Americans get better care, more effective care, and care that reflects the very best and the most up-to-date practice that is possible to provide.

And I want to finish this morning by mentioning another birthday. It has been mentioned here twice this morning, but is it so important, the Americans with Disabilities Act turns 15 next week. And it was a promise to the nation that we will no longer underestimate the ability of Americans with disabilities. And it is a special privilege forme to be working with all of you to help achieve that promise every day, and I want to end with just a little story that a couple of weeks ago, I sat in my office with kind of a new generation of CMSers, the up and coming some of the best and brightest minds, and I found myself having to tell them stories about the adoption of the Americans with Disabilities Act. They didn't know some of the stories. They didn't understand why we were talking about a birthday celebration. So I encourage all of us to find little ways to keep those stories alive, and to institutionalize them because yes, we as baby boomers are turning 60, but that also means that we have a whole new group of up and comers, and we have to make sure that our history is not lost. So thank you. I hope to be seeing many of you at the community level in the months to come as we work on our community based initiatives, and getting drug coverage to people who need it most, thank you.

## (Applause.)

MARGARET GIANNINI: Thank you, Jackie for that very clear presentation on where we are with CMS. And I just want to remind all of you that when our responders have completed, there will be time for Q and A, and so I want you to be thoughtful about some of the questions that you can pose to these experts. This is probably one of the best opportunities you will have to do that. But now we are going to go on to our next federal panelist, and the Social Security Administration as you know has an important role to play in promoting healthy community based living for both older adults with disabilities, and those who may develop disabilities in later life. I'm pleased to introduce you to Mr. Fritz Streckewald, assistant deputy commissioner for program policy in the office of disability, and income security programs at the Social Security Administration. Fritz has been part of the SSA since 1974 when he served as a claims representative and since 1981, he has held a number of senior staff and management positions, and was appointed to the position of associate commissioner for program benefits in January 2000.

The following year, was named the assistant deputy commissioner for program policy in the office of disability, and income security programs, his current role provides SSA wide leadership in managing the Social Security and supplemental security programs. It is my pleasure to introduce to you, Streckewald.

FRITZ STRECKEWALD: Thank you very much and good morning to everybody. I want to thank you Dr. GIANNINI, and I also want to send the regrets of Martin Gary. He lives and breathes these issues. He unfortunately, had been called out of town unexpectedly but he wanted me he to let you know he wishes he could be here with you. I particularly think this is a good time to be speaking to you. It is very opportune time for Social Security. We are in the midst of making programs changes in the disability program that we believe will allow us to

Peter meet the needs of aging people with disabilities. I would like to take you through that a little bit. We have a PowerPoint here and I have an assistant who is going to be able to follow along, I can't see what is on the screen here but just give me a yell if I get too far ahead. I think Social Security's role in this whole issue is to find kind of a basic premise that I believe is kind of self-evident, that cash benefits, medical benefits and the opportunity to work lead to improved health of an aging populations, obviously cash benefits provide for people's basic needs. Medical benefits provide for access to health care and medications, and the opportunity to work provides more self-sufficiency, and independence, so those 3 basic provisions, will provide that we give to the American people, we work with the American people, I think you can see that we have got quite an involvement in the issues of today. You are going to see a lot of data this week, I'm sure, and these are very simple little charts I'm going to show you, they are just kind of indicator, but there is a chart here that shows a correlation between work and health with people over 65, people who feel that their health is poor almost none of them are working, people who feel their health is good 50 percent or more of them are working that is a chicken and egg phenomena, but there is a positive correlation between work and continuation of health as a person ages. Now SSA's role again, we provide income support through the Social Security perhaps through the SSI benefit program. We establish entitlement to Medicaid

andMedicare. We also write now are beginning to establish entitlement toMedicare part D subsidies. Jackie mentioned a lot about this, in terms of what our role is. Basically, the subsidies help people with low income to pay the premiums for prescription drug medication which is part of the MMA. I wasn't going to go into a lot of detail on that because I want to talk about the disability program mostly but I would be glad to answer questions if you have them on this subject. In addition, Social Security provides opportunity for people with disabilities to return to work. So let me mention the two programs, the two major parts of our program, the aged programs, basically people 65 and older although you can retire at 62, you can get benefits at 60, we have about 32 million retirees and spouses receiving retirement benefits. About 1.2 million SSI gauged beneficiaries, these programs are fairly mature and straightforward, most decisions are made very quickly with the minimum burden to the claimant and we usually can send checks out within 2 weeks of eligibility. So we feel that this is a good solid program, and is not a lot of difficulty in getting the process to be responsive to the public's need. One thing I should note on the retirement program, Congress, I think anticipating that there is a good relationship between health and work, eliminated the retirement earnings test in 2000, so people who reached the full retirement age can work as much as they want without sacrificing any of their Social Security benefits and many, many seniors have taken advantage of that since the law was passed.

Now the disability program, is not as big perhaps in terms of numbers, but we can be honest a lot of our budget, administrative budget goes to the disability program, more than two-thirds because it is a much more complicated program, we have about 6.2 disabled workers with 1.75 million dependents, now those are the DI roles, on the SSI roles, almost all of the people, 5.7 million out of 7 million are on the disability rolls compared to the aged SSI. Now we also know that disability tends to increase with age or incidence of disability increases with age. As we see in this next chart, on our rolls, we can see very clearly that it is heavily skewed towards the older age groups, 50, 555, 60, up to 65, you see a greater number of people proportionate to the entire roll. This is not to imply that age itself is a disability. But it does indicate that as people grow older, they enter more disability prone years which I think we are going to hear more and more about this next couple of days.

Finally I had another chart, very interesting, this is a chart that basically takes 2 snapshots, we looked at our people on our rolls at 25 years and younger and looked at what were the basic spotty systems, the source of their impairment and as you can see there the light lines and the one is the mental disorders, which about 70 percent of people 25 and under on the roll sincere because of mental disorders, now look at the dark line, those are the 55 and older beneficiaries. And of course, you expect to see musculoskeletal increase quite a lot. As we all begin to experience a lot more difficulty with our joints and our limbs. Cardiovascular, of course is up, and neoplasms is another major cause, so not only do you enter disability prone years as you age, but the nature of the disability changes over time in terms of what it might be the type of impairment that may cause a person with a disability to suffer from it.

Now, one more chart here just to show you that we are aware that the baby boomers are coming too, because our disability applications have shot up and they will continue to shoot up as the baby boomers enter continue to enter their disability prone years, so we are getting ready for that. We always need Congress's help, but you know, so far, we are okay with that. Now, the rest of the session, I want to talk a little bit about what Joanne BARNHART the current commissioner has done to pretty much follow along some of the things started by earlier commission nears, Dorcas Hardy you have heard her, she has a great depth of understanding on the issues in the disability program, improvements were made then, subsequent commissioners are always trying to improve the disability program, joy an BARNHART came in and looked at the status quo and said she is not satisfied with it. It needs to continue to keep changing, she committed herself to improving the process, which she said was broken andto modernize the program to reflect modern day realities. What she did at a hearing, I don't know how many of you were there, it was quite memorable, she laid out a 25 foot chart for the Social Security subcommittee to see the disability process. And just by looking at it everybody got a very gut sense that this is a process that was very convoluted, and the sad thing about it if someone has to go through the process the hearing and appeals process it could take over 1,000 days. That is just unacceptable. So that needs to be changed in order to get people access to one of our main income support programs.

So what she did is that she kind of set up what I would call a two-part approach, she went to improve the process, and she exploring program improvement, improving the process we have already implemented electronic disability process, we are ramming it up in the rest of our offices about it we now have the capability of taking electronic applications right at the field office moving that work electronically to the DDS for a a decision to be made that can be moved to the hearing office for a decision, so it takes us away from paper bound work which is much more efficient and really builds a foundation for future changes in the process an program, we are greatly reduced the backbone of court cases with eye has become a concern we instituted new case process systems in the office of hearings and appeals and we are setting up a network of video conferencing to allow people not to have to go so far and present their case to administrative law judge, now the commissioner also has a number of other approaches or changes she would like to make, at a hearing on September 25, 2003, before the same Ways & Means Committee subcommittee, she reported about her thorough examination of the whole process, and she committed again to revamping the process and the program, and these - the way her approach as we call it now, which is still being worked on over the last two or three years, is based upon 3 questions that President Bush put to her when she met with him. President Bush seemed to get it. Because he has 3 simple questions which are the heart of the whole issue that we have to deal with. Why does it take so long to make a disability decision. I guess he had seen the 25 foot chart. Why can't people who are obviously disabled get a decision immediately? And why should a disability program beneficiary risk attempting to work after having gone through such a long disability determination process in the first place?

Well, she thought that really did strike at the heart of the matter, and her approach to continue to change the process and modern nice the program, that has been the foundation for it. Now modernizing the program, we are looking at how benefits from played, not the process but how benefits are paid and who gets benefits and what are the rules of the program. The first step on this actually I think happened in 1999, in a big way, the ticket to work legislation was passed, and it was designed to increase beneficiary choice and paying rehabilitation and vocational services. Legislation passed in '99, bee started rolling it out a couple of years later in 2004 it became fully rolled out. As you mostly are aware of the fact that it also established benefit planning assistance in outreach networks and protection and advocacy groups for beneficiaries.

And as importantly, section 234 requires the commissioner to develop and carry out experiments and demonstration projects designed to determine you know, the advantages and disadvantages of alternative methods of treating the work active of individuals entitled to disability insurance, so that gave her the funding to try some demonstration models which I will talk about in a minute, now I think the ticket started it, and there have been discussions probably 20 years, within Social Security about what needed to be done, but to get past the original structure of the program, I think it requires two paradigm shifts, and I think we made one perhaps we are getting there, and the other one we are still working on. The first one, I think, is that the old view that the kept disability work on opposite sides are almost mutually exclusive, if you are working not disabled, you are disabled and you can't work now that is an old view but that is how the original program was set up, of course the new view is with the right support systems people with disabilities who want to work, can work. And the ticket definitely helped in that, but there needs to be more in that direction, and I think the second paradigm shift, is something that is becoming equally as apparent as the first, we need to change the view and change the program street old view as you look at the program how it is set up, the medical benefits are secondary to cash benefits. We make a person, probably the only industrialized country in the world that makes a person be severely disabled, and then to get the benefits and then wait two more years to get medical insurance withMedicare. The new view is different, the new view is that medical benefits are instrumental in managing disabilities. And that is the demonstration models which I will be talking to you about in a minute.

Marvin GARE as you know has taken a look at the work incentives and he has talked to people across the country, and he has come up with a list barriers to work, I won't go through them all but it is an awareness that there are a number of issues and barriers that need to be overcome if we are going to allow people with disabilities to have any fair shake of getting back to work or to work at all. So what we tried to do, we showed this is Martin's chart it is the structure of disincentives as you can see in the middle there, the goal is to work, and the minimum of showing you what to do overlays on this chart and that has to do with the demonstration projects. The demonstration projects, they test the effects of new ideas, removing barriers to work, and provide justification for future legislative changes, and I will give you a couple of examples of the demonstration projects, the accelerated benefits project provides for medicinical benefits in 2 to 3 years and the support and improved health in return to work, and we hope to begin enrolling participants as early as 2006. The ongoing medical benefits demonstration, will provide health insurance beneficiaries who want to work, the pilot will target beneficiaries of HIV and immune disorders and will be conducted in several counties in California also beginning in 2006. There is a demonstration called interim medical benefits will provide medical benefits to individuals with no medical insurance whose medical condition would likely improve with treatment.

And then finally, another example of the demonstration project is called the mental health treatment center will test the impact of interventions on health care in job seeking behavior provide health insurance package or vocational rehabilitation. Now let me overlaw these demos, and other demos and some regulatory work that we are engaged in right now on the disincentives chart you can see each of the changes that we are bringing up. Address one or more of the disincentives. Now of the regulatory areas we are looking at is to enhance the ticket. We are not happy yet with the success of the ticket. We want to expand beneficiary choice. We want to make more EN's participate by perhaps changing the milestone payments, et cetera. The expedited reinstatement, obviously we are looking at expedited reenstatement after the beneficiary stops work, looking at continuation of benefits to certain individuals who participate in VR, particularly for people 18 to 21. And we are looking at changing some of the PAS rules, to look at eliminate in 48-month time limit. So I guess there is a lot up here and I apologize if I flew through it really quickly but I think is essence of what I'm saying is that Social Security is starting to get it. People at Social Security for years, have been working towards what is now starting to come to fruition. You have to lay the groundwork. You have to move slowly. But these demonstration projects will provide for us the real date data to support legislative change and major program change, so I again would be very glad to answer questions about these issues and any of the other Social Security issues that you may have, thank you very much.

## (Applause.)

MARGARET GIANNINI: Thank you very much, now we will hear from our Respondents the first one is jUNE iSAACSON kAILES, who is a consultant disability rights advocate social worker and a national leader in the independent living movement for people with disabilities, she is adjunct sometime professor and Associate director for center for disability issues and health professor at western university university of health sciences in California. She also was presidential appointed to the United States access board in 1995, to 2003, she served as chair and vice chair. Please welcome KAILES.

JUNE KAILES: Thank you, we as responders were told we had 15 minutes apiece. We got a note that said we now have 5 minutes a piece, so I need a little accommodation. I have never perfected my ability to speed talk. So bear with me. Probably like many of you, I refer to myself as a living laboratory regarding aging with disability. Just take a look. Here it is. I can talk about it firsthand. Many of us have lived with disability for years, and we had an early introduction to the so-called golden years,

or aging experience. LEX and I often speak of it is accelerated and we get an early pilot on what is going on, when my mother and others talk about coping with aging, I say but I already have that now. So it is hard to confine my responses. But I will.

To getting it right, I like that, getting it right in areas sacred, in the areas sacred in the health and independence, we need to look at the tools that allow us to keep going, and prevent the world from unnecessarily closing in and becoming confining. So how do we translate those words, the mantras into reality, like quality of living in the community?

I want to applause -- with the underlying values of choice and control. But we need to look at the reality of technology, and how it translates into living better and longer, and the questions in today's world remain how do we get it? The pivot tall role that assistive technologies, and DME play in prevention, and rein reducing secondary conditions and injuries has to be recognized, you all know what DME and technology includes, but mobility and augumentative communication and CCTVs, and prosthetic limbs, and glucose meters just to name a few, these are devices that are critical into helping people with atypical limitations of all ages. Improve their health and their mental health, and their participation independence, productivity and integration. In the home, in the community, and in the workplace, and at school.

Technology helps prevent the costly medical problems due to mental and physical deterioration depression, pressure sores, injuries, as well as some reduced personal assistance costs. So, for example, real mobility as a convenience item, is absurd. As I recently explained to Blue Cross while making a case for having a biyearly scooter battery and a couple of other small items, which would extend the life of this 15-year old scooter, I'm not using the scooter to make a fashion statement. Short sighted policies which only allow payment for strip down, noncustomized and sometimes inexpensive devices, like heavy manual wheelchairs cause downstream preventable problems, and high cost interventions that deal with upper extremity injuries. Denying coverage for simple wheelchair cushion, means paying \$50,000 later to possibly repair a pressure sore. -- it may mean treating expensive broken bones and injuries later.

We applaud DMS in the shift for the -- for coverage and mobility assistance to more functional standard. This is progress. But it is not -- there is a lot more work that is needed. Medicare pose in the home restriction on mobility devices, must be modified so that people obtain what they need. Federal health programs and private payors have to recognize that improvement in function and prevention of primary and secondary injury has to be a part of determining whether assistive devices and technologies and related services are medically necessary. A big policy issue.

We need to look at increased federal funding that has to be committed to the evidence based regarding the advocacy and the cost-effectiveness of coverage of these devices and services, a recommendation here, CMS should modify their an at the quited inhome wheelchair coverage policy, which restrictions coverage on mobility devices only those devices that are reasonable and necessary for you inside a person's home.

By denying a basic mobility tool, this restriction in the long run is most of more costly, and limiting department health community integration of people, who rely on chairs to function outside of their homes. You know the reality is many people like myself can get around their home via wall walking, or what we call furniture searching, or using kind of a manual wheelchair, or a cane or walker, but outside the home, these same methods are unsafe, confining, and oppressive, and there are many of us in this room that could have easily been in the group of people whose benefits deny them access to this liberating technology.

The antiquated restriction, and interpretation continues to unnecessarily confine, imprison, did he value on press people with disabilities of all ages by compromising their health, independence, self-sufficiency, and social connections. So increases, we need to lift these restrictions to increase health and safety and decrease the development of secondary conditions associated, for example, with isolation. By not lifting these restrictions, there is an increase of cost in terms of treating what we know from research are predictable and preventable downstream expensive conditions, which ironically are covered byMedicare with little or no question. By not lifting these restrictions, we ignore, and health care providers to change. They will encounter, to -- they run counter to the OLMSTED decision and the ticket to work program, and they cost us advocates in the disability community, to question the administration's commitment to their new freedom initiative, which supposedly is aimed to increase independence, and community integration of people with disabilities. So the recommendation is, if the administration is unable, refuses to change this policy, then we, the people, must come might with Congress to promulgate a legislative remedy, so in trying to stick to my expressed time frame here, I will discharge you all to look at some of these other policies. Look at the importance of expanding the definition of medically necessary, to include maintaining function.

Look at the issues around ensuring stronger ADA enforcement in health care so that we ensure physical program, and equipment, and access to medical equipment because today it is not a reality in health care. 15 years and counting, access is still not a reality in health care. Look at a a benefit that is needed by many people who deal with problems navigating the health care system in terms of their complex issues. But to do so, to offer coordination with an offer lay of choice, self determination, and honoring people with dignity. So in the next hours, I guess we need to remember that life is short, and that we need to focus on applying a filter to everything that we do, that as Dr. G says, converting the words to reality, because if we don't, they just remain empty mantras, empty words and empty promises, thanks.

(Applause.)

MARGARET GIANNINI: That was wonderfully done because she really compressed her remarks so that you all have an opportunity to have a Q and A session, and I have got to impose on Bonnie Cramer to do the same thing, but Bonnie is --

BONNIE CRAMER: Let me ask you to skip the introduction then, that will give us some more time.

(Laughter.)

(Applause.)

MARGARET GIANNINI: I only follow orders. Bonnie, Bonnie has been on the AARP since 2004, she recently retired from a 30-year career with the North Carolina Department of Health and Human Services and the governor's office on state budget and management. She also served for a decade with the division of aging and directed that division during a period of rapid development and community based services. She served on many national committees and advisory commits, and she received numerous awards for her work. Bonnie it is yours.

BONNIE CRAMER: Thank you on behalf of AARP's all volunteer board we are very, very pleased to be a co-sponsor of this mini conference. As has been take itted here today, the aging and disability communities share many a-agency days, and this conference is an important collaborative effort. Many of you know that AARP is very proud to represent 35 million members, age 50 and older across the country, and we strive to help our members and other older Americans live with dignity respect and a sense of purpose as they age. Social Security andMedicare are key elements for a life of dignity and purpose, and this is also true for persons living with disabilities regardless of age.

I would like to also acknowledge as others have, the upcoming implementation of Medicare part D. Right now AARP is preparing to launch an education and outreach campaign to encourage beneficiaries to be aware understand, and take advantage of this new benefit. ForMedicare beneficiaries, this represents a Giant step forward in relieving the burden of excessive prescription drug cost to older persons and to persons with disabilities. And yet, we at AARP have not lost site of the improvements that still need to be made which include eliminating the assets test, eliminating the doughnut hole, and allowing safe importation of medications from other countries. We have made an excellent start but following through, finishing the job, must be our goal. Now, Social Security ranks high on our nation's domestic policy agenda, and therefore, Social Security disability insurance must also rank high. SSDI covers 159 million workers and their families and about 8.1 million workers and their families currently receive these benefits. About 17 percent of people receiving any Social Security benefit. AARP believes that we must strengthen Social Security for our children and grandchildren but the solution to adjust solvency cannot be worse than the problem, and therefore, we say no to private accounts funded with money diverted from Social Security. Now, serious proposals for changes to Social Security must continue to provide adequate income support for persons with disabilities and their families. We expect them to maintain the basic structure of the current system to preserve the social insurance nature of the disability program and to guarantee benefits with anal inflation adjustments. Now, AARP also supports the following measures related to Social Security disability insurance. We must continue efforts to expand work incentives through the ticket to work and work incentives improvement program. There are far too many people involved in this effort, and as long as these programs provide economic security health benefits and don't endanger the long-term integrity of the Social Security trust funds, we must work to broaden the availability of vocational rehabilitation, and employment services, and we encourage the expansion by SSA of a pool of alternative vocational rehabilitation providers.

We also know that early intervention, rehabilitation intervention, both physical, an vocational increases the likelihood of employees with disabilities returning to the workforce so we have got to lengthen that 25-foot chart. We must also we have to shorten that 25-foot chart, we have been lengthening it for many years, we must also improve the disability determination process, including developing ways to include the appeals process at the end of 2004, there was a backlog of nearly 625,000 claims. That is unacceptable. While Social Security Administration's funding has been increased it is has not kept pace with the increased workload due to the rapid growth of disability claims, and therefore, AARP urges Congress to revise the Social Security administer -- provide the Social Security Administration with additional dollars for strengthening to serve disabled applicants and beneficiaries. I would now like to share quickly a few of our thoughts at AARP on some health care and care giving issues that effect both older people, and people with disabilities and of course Medicaid plays an important role in this arena, you should know that without question, the majority of AARP's members want to age in place, they want to stay in their homes and communities where they have connections, and where everybody knows their name. We strongly support our member's preference for home and community based care, and unfortunately, as we all know, Medicaid has an institutional bias that must continue to be worked on and needs to be removed, people need greater access to home an community based services and supports, and since family CAREGIVERS are the backbone of our long-term care system some people say they are the longterm care system, we must support them also. People should be able to live independently in the setting of their choice and they should be able to maintain control over their lives. So we must maintain Medicaid as a safety net for persons who need help paying for long-term services and support. AARP opposes arbitrary cuts and caps to Medicaid. We are working to ensure that any cuts to Medicaid by Congress does not harm beneficiaries. People also need more options to pay for their care. Medicaid has become the default for long-term services and supports, most off institutional because many people do not have other options for payment. Congress should provide Americans with more options for planning and financing long-term services and supports. Now specifically, AARP supports expanding home and community based services, including money follows the person demonstration, we support providing a \$3,000 tax credit for family CAREGIVERS to help with the cost of caring for a loved one, we also support providing a tax deduction for long-term care insurance with strong consumer protections. We calleled for adder

more protection so that the long-term care partnership program can be expanded, we also call for examining how lower cost, reverse mortgages can enable people to stay in their own home and maintain their independence. I think we all look forward to the day when older Americans and people with disabilities can live independently in the setting of their choice and have control over their lives, thanks.

(Applause.)

MARGARET GIANNINI: I think the Respondents did a beautiful job in responding to the issues.

(Applause.)

MARGARET GIANNINI: Do we have a roving microphone?

>> We do.

MARGARET GIANNINI: Those of you that have questions, just raise your hands, and while you are doing that, do our panelists have any fast reactions to the Respondents that you would like to make right now?

JACKIE GARNER: I just want to say thank you to June, an Bonnie both. They both raised some great points, I think we are all in agreement on the end goals. It is how we get there. I did just send a question to my office on the little black berry here, because I wanted to check specifically, June raised a lot of assistive technology issues. The one specifically about wheelchairs in-home restrictions, we think that secretary LEVITT repealed that recently, but I can't confirm that. So we are checking, and I told Dr. GIANNINI I could call her with an answer.

MARGARET GIANNINI: I think that is imminent, as far as my information is concerned, so we will let you know.

FRITZ STRECKEWALD: If I could just mention, again, I think a lot of what you are saying here is what we are trying to do. We are somewhat restricted as other federal agencies are, the Congress has not been able to give the president's request for the yearly budget so none of our administrative efforts -- some of them are a little restricted, I think in some areas you talked about the hearing backlog, 625,000, that is an unacceptable level, the commissioner set a goal for 300,000 pending, and as she sees what budget we have each year we have to move that out. Because she still has a strong intend to meet the 300,000 pending, which is really not pending, this is cases that are being processed rather than cases sitting there, so we are working on some of the other things that you encouraged us to do.

MARGARET GIANNINI: Thank you, questions from the audience now. And if you will just raise your hands. Do we have any particular questions from those of you in in the audience? Yes. Milton.

MARGARET GIANNINI: Identify yourselves your name and what youdo.

>> Good morning everyone my name is PONTE I'm a member of the national council of disability, first of all I'm the father of a disabled person. LUCY, my daughter, and just a second question, you talk about the high number of disability claims pending, and I wonder if there is – is there any effort on the part of the Social Security Administration to coordinate with the Department of Justice in terms of processing the claims? You know, I represented a commissioner in Federal Court in many of these cases and I have seen a number of cases that could probably have been taken care of before talking to the US Attorney's Office, but I wonder if there is any effort along those lines to move faster, those resolution of those cases so that you can provide an answer to those claims?

FRITZ STRECKEWALD: That is a good point because as I mentioned when commissioner BARNHART came into office we had an unacceptably high number of cases waiting to get to court because of the certain amount of preparation that has to be done, we were getting some very severe letters from the judicial council saying that at some point we are going to have to hold somebody in contempt if we don't get these cases quicker. So in regards to making sure that the cases do not wait at Social Security waiting for somebody to do some of the photocopying and other work that has to take place, we solved that problem, we bought some massive photo copiers and other things that make the process easier, and we have worked with the courts to try to figure out if there is a way to have fewer cases going there, which basically end up getting sent back to us, and I think the commissioner BARNHART disability changes that they hopes to announce soon will address that, by building a lot more accountability into the each of the adjudicative levels, we hope that will address the issue that you mentioned because it is a serious problem.

MARGARET GIANNINI: Next question. Identify yourself.

Q. Yes, I'm Matt BAAKE from Gallaudet University, the director of the rehabilitation engineering research center on hearing. And I wonder if any of you would like to comment on any activity with regard to hearing aid benefits for people on Medicare?

JACKIE GARNER: I can take a crack at it. I'm wondering if there is a question in there, because is there something specific that other than a general comment.

Q. Is there any activity with regard to bringing this benefit to people?

JACKIE GARNER: It is something that I would have to check on honestly. I could not answer that at this time.

MARGARET GIANNINI: Social Security?

FRITZ STRECKEWALD: I don't know the rules on that. I think that is CMS.

MARGARET GIANNINI: We will get you the answer. Make sure we have your name and address, and we will get the answer to you. And any others that are interested in that question, will get it back to you too. Next question.

Q. High my name is Mike KUKLAR from the center of – the independent center of Northern Virginia we have a special lift at the independent center and we also facilitate student directed personal assistance Medicaid assistance waiver, the issue that you all talked about assistive technology, beyond the point that has already been addressed, the issues of people making determinations of eligibility for assistive technologies like seating, proper seating and other types of things is a very, very important one for people with disabilities. Kind of the issue is where you stand on the matter depends kind of where you sit. And it is so frequent that people with very little personal or professional understanding of the functional areas of living with disability are making the determinations by applying the rules federally, and I would say somewhat arbitrarily, to weigh in on approving or disapproving some very, very important assistive technologies that make a critical difference in independence, and help the community integration and work and other types of outcomes. So my question is, beyond what has been addressed in the impending maybe the black berry that you are getting, what efforts are federal agencies making to ensure that when a recipient or a beneficiary needs a piece of assistive technology, low cost or high cost, that that assistive technology is provided with an eye towards minimizing secondary incidences of disability, or an eye towards just providing what people actually say they need, and are they in the best position to help determine what it is they need?

JACKIE GARNER: My immediate answer, and I have to tell you it is one that I have had a long-standing interest in. I had the privilege of working in a foundation with the person who designed quickie wheelchairs, so I really it is engrained so deeply in me how important this issue is. I think the first response is that we have to continue and do even more with for example, the office of disability in training and educating our -- those people who are making the determinations, and the eligibility decisions. I think it begins there that we must -- that we must make sure that that information is available. We have to make sure that the appeals processes are appropriate. Is there anything Dr. Giannini you would like to add?

MARGARET GIANNINI: I want to underscore that it is a major priority in the office on disability to get to the core of knowledgeable and trained personnel that deal with persons with disabilities because as we all know, that the different disabilities and different questions have requirements of the different disabilities are different in each case, and one size does not fit all. So we are working on that. How soon it will happen, it usually depends on dollars in terms of whether we have money, and we try to work that out with CMS right now, so all I can tell you is that I I have hope and I'm working on it.

JUNE KAILES: I'm pleased to hear that maybe the black berry announcement may be imminent and I'm waited with baited breath, but I urge you all that that doesn't let us off the hook. That it is much more than CMS. We need to look at private carriers and coverage as well. And the hearing aid issue just to restate that, and underline it is so critical. Where I sit in the trenches, again it seems ludicrous that maybe one hearing aid will be funded but not two. And digital hearing aids if anything gets funded at all. I mean the hearing issues are huge and we have to include that in the disability issues.

MARGARET GIANNINI: Let me respond a little bit, so that you won't be frustrated about the deafness issue. It is a major priority in my office, and we have had an expert working group for over 10 months now with recommendations that we have brought to every federal department. A lot of what we are talking about also falls in part C of the idea, and you -- there are going to be hearings on that and I'm going to take this opportunity to urge all of you to be at those hearings, express your concerns, because I think that the assistant secretary is very willing to listen. I have had many meetings with him, and we are working on it. But that is only one piece of it. And it does include hearing aids and the whole spectrum of the deafness and hard of hearing problems. So as far as the question with CMS, we will get that answer to you as well. We have time maybe for just one fast short question.

Q. I guess it is me since I have the microphone. I'm Jane west, I'm here on behalf of the association of assistive technology programs. I just wanted to make sort of a general comment and would be very interested in the opinions of the esteemed panel. It seems to me that June really hit something on the head when she related her conversation with her insurance company in trying to tell them that this was not a convenience that she was interested in but an essential piece of equipment for her to function. I think we run into this in so many areas of disability. In education where students are seeking accommodations. In health care, where I tells that wehave talked about today are absolutely essential for basic functioning. There is a perception that these are somehow Cadillac, when really a VW will do, or even in -- among those of us who are professionalness in this field, who have a sense that you know, and maybe this is a place where aging and disability, there is a little bit of a difference perhaps. Everyone has an aging experience pretty much. The unique aspects of the disability and aging experience don't seem to be understood in terms of --

MARGARET GIANNINI: Did you have a question?

PARTICIPANT: , I was interested in people's comments on that, I think it is one reason why we haven't made as much progress under the ADA and perhaps the public relations campaign might be something.

MARGARET GIANNINI: I think you are perfectly right and your comment is well taken but I'm sorry we are out of time. And we have already taken some time from your break, so I appreciate your patience, thank you very much.

(Applause.) Where.

- >> Our next speaker will be Senator Brownback who is breaking away from a complicated senate schedule so we would like for you to take a break now for about 15 minutes. We have some beverages just outside the room. The accessible bathroom is down the hall just on the other side of the business center. We have please be back in 15 minutes.
- >> If people could take your seats we are going to go ahead and get started.

MR. IMPARATO: We are going to go ahead and get started. Good morning, everyone, my name is ANDREW IMPARATO I'm and I'm the president of the association of people with disability, I'm one of the members of the planning committee, senator Brownback from Kansas has joined me and they have been scheduling things all morning and you has to go back to vote so he is going to be very brief, so please welcome me in welcoming senator Brownback.

SAM BROWNBACK: And I want to thank you all for being here, and the work that you do, and what you bring to America, and what you bring to this society and culture because it is a beautiful thing AND IT HELPS ALLOF US. And I just got called for a vote so I rushed here and now I'm going to rush back to be able to get back for the vote. And I apologize FOR that, but that is MY first and foremost dutY. Andrew has done a GREAT job. I want the talk real quickly about one bill that we are putting forward. AS A MEMBER IAST YEAR OF the commerce committee, there I found a number that I didn't realize, but that 80 percent of the people that have children in utero that are diagnosed as Down Syndrome, the children are aborted. And I thought this is a terrible number. It is a terrible high number, and so I joined together with senator Kennedy, and we went together to put together information to provide for people when they have that diagnosis of what is taking place, of options available, of waiting lists that exist to adopt children with Down Syndrome, so that we hopefully could pull that number down. It was part of a bigger package of issues that as we get more prenatal diagnosis of various issues, that people not immediately say well okay, I don't want this child because the child is quote unquote not perfect. Because I believe every child is perfect. And I think most people look at every life as unique, and beautiful, and that this is something that we can do to celebrate and to work with, and we did also with the bill help provide assistance to low income individuals who have children that have particular physical needs. Senator Kennedy required that saying okay, we are going to work on this and we also need to work to provide assistance to families in that situation, and we did in that bill.

My point of saying all that is that we are trying to reach and pull together on commonalities where there has BEEN a lot of divisiveness in the past. I think we should celebrate the Americans with Disabilities Act, it's movement through and what it has done to transform the society. My predecessor, Bob DOLE, in this seat, a leader on this issue, and I think this is probably one his greatest achievements while he was a legislator. I think I can say that with some assurance, and this is a guy who was a prominent legislator, a Michael Jordan of legislation. He really knew how to get things through and yet he considered this one of the key things that he had done to change and transform America, and to make us a more beautiful society where we celebrate each and every life regardless of who it is, where that person is located, what they may look like, what they may do, any sort of advantages or disadvantages that they may have. Each life is beautiful to me. It a is a child of God and should be celebrated and supported. That to me is a positive viewpoint and one that we have to build on and need to. Thank you for being here, Andrew, great works. Gene, I'm sorry that I couldn't be here longer. I don't think there will be a whole lot of debating. I think we will be looking for areas of common ground and thank you for what you give to all of us. It is really invaluable. It is very precious, God bless you all. Thanks.

## (Applause.)

ANDREW IMPARATO: Thank you Senator Brownback and thank you for getting him here. We are going to have more time with Gene Sperling which is not a bad thing. Gene Sperling was a key architect of economic policy in the Clinton administration. He wears a lot of hats. He just got back from a conference in Paris and he came back a day early to be with us today, so we really appreciate that. Gene is an advisor on west wing, actually written some content for the west wing. He works for the council on foreign relations, and he is considered president Clinton considered him an MVP most valuable player of his economic team. And the economy when president Clinton was president was robust, we saw a lot of growth, and I think Gene Sperling deserves a lot of credit for that, Gene is also very interested in disability policy and in particular he is interested in what can we do to make it easier for people with disabilities to work and to get health care that they need and supports that they need to be able to continue to work, as they age. And so Gene is going to make some remarks for you all, we asked Gene and senator Brownback to think in terms of a future political agenda that could bring together the disability and the aging movements in the context of a presidential campaign or other high profile national platform. So in that context please join me in welcoming Gene Sperling.

Gene Sperling: Well, thank you very much. Thank you for having me. I did as Andy said, I was in Paris last night, and I was supposed to be there for another day, so I want some points for commitment.

## (Laughter.)

Gene Sperling: But I will say that there is -- that there is something about this speech which always makes me a little uncomfortable. It is the difference between when I often go speak and I'm supposed to give a speech on the overall economy, or then I have to go speak to people who work in these security you know some very specific thing and I always think to myself, well, the one thing you don't want to do is go right into the heart of their area, because everybody in the crowd is going to be more of an expert than you and yet of course that is what people want to do, so I'm going to do with the intimidation that so many

of you are going to be more experts on policies on disabled Americans, Americans with disabilities, I still want to try to bring what a little bit of my larger perspective is. Now, the first thing I have to talk about is the podium here, because I want to let you know one of the really good things about, there aren't many good things about me leaving the White House, but podiums are one of them. The podium in the Clinton GORE White House, and this is perhaps my little sense of -- and I don't want to in any way claim to say that I have any sense of what it is like for -- to be a person who has a real disabilities, and has to operate in a world where people don't have -- when the world isn't designed that way, but I want to say in the Clinton White House, podiums were designed for very tall people. Particularly, Al GORE, and bill Clinton who were 6 two-and-a-half, and 63-and-a-half respectively. Now I'm 5, 5, and there is a little history behind the fact that I'm 5, 5, because I'm actually 5, 5-and-a-half. And we had a whole debate about this on my staff when I was in the White House, because you know the question is, should we say when they ask for your height that you have 5, 5-and-a-half? Well, obviously there is different choices. 1, you could round up, and say I was 5, 6. But with all respect to senator Brownback and the years we were there, that probably would have led to congressional investigation.

(Laughter.)

>> And then --

(Applause.)

>> And then there was the view that we could just say I was 5, 5-and-a-half. But you know, it just seems like when you have to mention that half inch, maybe you are just trying a little too hard. So I finally settled on the fact that it is 5, 5. So that is is the official -- that is the official release. 5 foot 5. So this kind of issue on the podiums was not a big problem until what was perhaps one of my most exciting moments of my life, December 13, 1996, when the thing you always want when you are a loyal deputy happens you get promoted, I had been the deputy National advisor to Bob Rubin and Laura Tyson, and after President Bush was reelected, he chose me to be the National economic advisor. When you are the deputy you prepare so many people to go through the process where they are nominated and the announcement with president Clinton, and I thought well I'm an old pro at this, and I was really. I kind of knew how the whole process worked, I knew how to write my remarks it is right way, the only thing I hadn't totally thought about was the podium, so here we go out, and they announce at the last moment only my mother and father could make it on time, but fortunately it was on live C-SPAN and LIVE CNN because they WERE ALSO appointing sENATOR bill daily AS COMMERCE SECRETARY AND Richardson to be head of the UN. So we are on the air and president Clinton says I'm choosing James, and I come up to the podium, and I would tell you that there is usually a little box near the podium. That was really put there more for Bob RICE, and Donna SHELELLA than myself. This is my big moment and I come down and I look and oh, my God, there is no box. So reminiscent of my days slow dancing in high school with women 5 foot 11, I got up on my tiptoes as high as I could, and it looked something like this (indicating). And so I'm thinking, you know, just persevere. Nobody will really notice, and as I'm looking out in the crowd, nobody seems to be too bothered by the fact that they can just barely see some of my head. Unfortunately, I do -- I'm disrupted about eye the fact that I can hear two people laughing. The bad news for me was that they were behind me.

Bill Clinton and Al GORE thought it was the funniest thing they ever saw. So on live national TV, president Clinton laughing hysterically walked up to the podium, asked me to step aside, this is a big moment in my whole life, my relatives and family, they are all back at home around the TV set, president Clinton asked me to step aside and I then learned like the only thing I did understand about the White House was that there was actually this little button that you could kick and a step would come out. So president Clinton says step aside, the president of the United States the leader of the free world, I come back, now the little step is out, I come back to my audience, and I you know, step, I go up like this (indicating), and the CLAPS and that was my first 10 seconds of as national economic advisor. Some people say well that was a sign of things to come, but I think in the economy, I would say that you know after that, things got a lot better. But anyways, I really am happy to be here, and one of the things that we did start to work on, you know, one of the things you always say to each other when you are in the White House is you know, that there is a saying that for you know, for every hour you are in the White House, you are going to spend 10 hours thinking about the things you wish you did, and that you didn't do. And one of the things I find is you also spend a lot of time thinking about the things you actually did and wish you had done more of, wish you had started earlier on, and I feel that way a lot about policies related to work and people with disabilities. I think that we did start looking at this issue more, and we did a new market's initiative in our last year. And we were looking at kind of new markets, and the idea was to go to areas in the country and you know not just think of a new market and new economic opportunity but we are right in our backyard -- where in our backyard were those opportunities, and after we had done a couple we talked to president Clinton and we said instead of thinking about that geographically we should think of the new opportunities in our backyard in terms of Americans with disabilities particularly in light of the new technologies that are coming out. Are we really thinking about this, et cetera? And so you know, many of you we worked with on that trip, and we went to Flint Michigan, and we did quit a lot, and we learned quite a lot too, just as an example of the thing we learned, we brought in -- one of the wonderful things about being in the White House you can wave your magic wand an every expert will come around to the table, I kind of somehow lost that magic wand the last five years, but we brought in people, and we said you know, why with the different internet technology -- we did one thing just on the internet and we brought in and we said you know, under the kind of notion that the internet you know, can be either kind of like the next curb or the next wheelchair ramp in the new economy. It can be like another obstacle or it can be like a way of paving new opportunity. And one of the things we learned right there which is very interesting, was a lot of the software designers, a lot of the hardware designers a lot of them told us the same thing, they said boy when you have to design a program or a technology,

and somebody comes back and tells you you have got to change this, it is really difficult for us. It is really expensive. We have worked years on that. They said but you know what? This would not have been hard if someone just told us that at the beginning. They said for us, and look I do not know their world at all. But the message was the same. The message was, if we were told from day one that whatever we were doing had to have this type of accessibility, it is not that hard for us to do it at the beginning. It is hard to go back and redo the whole thing. So it was kind of one of the lessons that we learned right there, and that was one of the things that we put out to the entire government as we were leaving in 2000, which was anything that at least federal government was doing in technology this should be thought of at day one not later, because it is the right thing but also is clearly the efficient thing. Now one of the -- to kind of step back, or to step up 2 miles higher, let me give the following point -let me tell you I was just in par raise bus I run a center at the council on foreign relations on called the center for you any vertical education and I work on the issue of making sure that all children in the poorest countries can go to school, 104 million poor children 6 to 11 will not see the inside of a school this year and I'm a very large advocate and spend over half of the time in my life on this. And one of the things that I always go back and forth on, is that people will make the case that education is a right, and make the moral case, and make the spiritual case and the humanitarian case and the religious case, and then we run over and say let's make the economic case, the health case and then we start trying how it is good for the economy, an runs different kinds of diseases, but you are always kind of going back and forth because then if you are making too much of the economic case you want to go back and remind people well, whatever the studies show it is just the right thing to do. Americans saw the TALIBAN keeping little girls in Afghanistan from going to school. They didn't need studies they thought it was the wrong thing, they thought it was a crime that the little girlness Afghanistan don't go to school and if we let them know this rural Africa that was happening by the 10s of millions, they would feel the same way. Well, I feel a little bit the same way when we are talking about some of these issues. On one hand there is a certain degree that you feel like we as a society, as a government, as a collective, should just be doing these things because we have such a fundamental belief in opportunity, and we have such an individual belief in every individual being able to rise to their potential. But this is an area where I think we have undersold the economic benefits. And I want -- Andy said to look out a little Browder and the way and die and I started talking about this and I'm not doing this to sell books but I have a book coming out called the progressive – and one of the points that I make in the book, even though right now we are so worried right now about the job creation, whether there is enough jobs what the competition from en-INDIA and China is going to be let me show you what the demographics going forward, we have generally relied on having more workers by one thing, population growth. If you look over the last twodecades, the pool of workers between the age of 25 and 64 grew 44 percent, so in other words, just by demographics. Just by kind of childbirth statistics, we have -- we had 40 percent growth over the next two decades in workers 25 to 64. Now, over the next two decades, how much will the growth in the labor force between workers 25 and 64 be? And the answer is zero. Zero. We are not going to have an increase in growth in the labor force demographically. Now, why does that matter so much? Well, it also means that the reason that we have had more college workers, more skilled workers has just been that we have had a higher percentage of people - we have had more and more people coming into the workforce. Now, so in other words, when you say that over the last two decades at least we had a growth of at least 20 percent of people have college degrees or skills that was happening a lot because we were just having more workers. If you are nothaving a growth in the labor force, what does that mean for your economy? That means you have to have a higher percentage of your existing workers having skills and being able to work. So when you look over the next 20 years, we just can't sit back and say, well, you know, of course we are going to have more skilled workers in our country, because America just you know grows, our population grows and as it grows we are going to have a more set pool of workers. And the question that is going to be, is are we as a country going to allow, going to take action to ensure that the people who are not participating fully, that a higherer percentage of them are getting the skills to contribute. That is a national economic imperative.

Now, you know, perhaps you could just rely on immigration, perhaps you know people will start having more children. None of those things seem as likely. So the question then for me looking for the pro growth progressive, what do we need to fit both of our values, progressive values but what is also best pro grow, how can we help different people, and the book pro growth progressive basically says there are a lot of things that make sense economically and make sense for our values. This is a perfect example. You have heard all of the statistics about how many more workers China, India are educating, engineering, et cetera, but the fact is, is that we are going to have to change the composition. So when I look at my -- the book I start asking, who is being ignored in our society? What is the talent right now that is being ignored? And I think that the truth is, is that much of our workforce policies, when it comes to people with disabilities, is still in a caretaker model. It is still in a caretaker model. And what I want to say looking forward, is, we should say no. This is a national economic imperative. You know the unite NEGRO college fund the mind is a terrible thing to waste. We don't have any more minds to waste. We can't just rely on population growth for our workers. Now if that was the attitude from an economic policy perspective, then you wouldn't just look at these issues as oh, well we will just deal with this with Medicaid, this is a special interest issue. You know, so when Andy says thinking big, I think the big issue is to start saying, this if you look at the future workforce, is a national economic interest story, which is how do you go through all of the policies? All of the policiness the Federal Government, and just say, does this policy make sense if our goal is to have a higher percentage of our populations in the workforce. Now, you know, again I don't have to tell you the statistics. 77.5 percent of Americans without disabilities are in the workforce. 77.5 percent, and a very large percentage of that – those who aren't, are not out of choice because they are in school or caring for a child. We know the number. It is exactly half. 37.8 percent. And Andy was very nice to talk about the Clinton years, but we all know the truth. Americans when it comes to -- Americans with disabilities in the workforce, they did not share -- things got somewhat better but it did not share to the same degree as other workers did in the economy. And we have to address those and go through that. So my you know, what I think and this is not just what I'm suggesting you do. This is what I want to do, this is what I personally want to do and work on. I want to start looking through every single aspect, and I think that when we do so, we have to break out and start trying to you know, you need to get more people, more economists looking at these issues. So now for example when people are debating Medicaid cuts, what is the debate over? It is a debate over fiscal policy. It is a debate over budget, it is a debate over these things. It should be a debate about the fact that when you cut Medicaid you are going to squeeze all of the buying procedures that came from the ticket to work act, all of the options that could be allowing states to give greater options for people to both work and receive the assistive technologies that they need. That should be -- if we are going to have a serious national imperative to have more skilled workers, we just can't look at that as just being a Medicaid issue. We should look through on SSI everywhere, and then I think you need to go the next step, and this is the one nobody likeses to do. I like to just say oh, you know, come here and say this is what president Clinton did, you know, we reauthorized the assistive technology act, we reauthorized you know, we did the ticket to work act, we are done. Let's just be honest. A lot of those things have not worked as much as they should, President Bush has put forth his New Freedom Initiative. The numbers of people that are actually benefiting from these are not impressive. They are not things people really want to brag about. Why is that? Again, if it is a national imperative for our workforce, we ought to know. Why don't more of the people who provide employment services you know, what is you know, is the ticket not generous enough? Why don't they have an economic incentive to be out there advertising, saying come to us, take our incentive to us, it is just the opposite. They don't think there is enough benefit for it. So my recommendation is that we go through each one of these provisions for a future national workforce provision with the idea that we cannot only waste anybody, we need more people, America will fall behind if we do not use the workforce talent that we

Now one of the issues that I think will rise, and I think this will be a workforce and a moral issue, is when we took president Clinton to Flint, he used the eye gaze technology, which he really wanted to do because he had a friend, Joe Martin, who had written two books, simply with movement of his eyes. And so we brought the technology there, and everybody was pretty excited about it and we asked how much does that cost? And it was 50, 60,000 dollars. There was an article the other day in the paper about -- which was amazing to me, about soldiers who were -- soldier whose have a technology -- again, enormous talks. Enormous cost. When we were in the White House, we were always looking at kind of a digital divide, and the digital divide when we looked at it are the technology divide, was between well-off Americans, and people lived in urban areas, but I think we are going to have to confront a different kind of technology divide soon, a technology divide where actually, if you are -- have a serious disability, but you are fortunate enough to be in a well off family, that you actually can get some of the technologies that can make it easier for you to function, for you to work, to be productive. And we are going to have to ask ourselves when those technologies exist, what is the moral and economic case for not making sure they are widely spread? And I think from a moral point of view --

## (Applause.)

Gene Sperling: And I think from a moral point of view our case is strong but I think we should do a better job of the economic case as well, so \$50-, 70,000 dollars might seem or while miningly expensive but is it when it is the difference between a person perhaps being a taxpayer for 25 years or not being a taxpayer or does it actually pay for itself. You know, here is just one idea. This may be a bad idea but it is the kind of thing that we have to think about. One of the things that we implemented when we were in the Clinton administration, we wanted people who had big college loans to feel like they could go do public service, so you say pay a part of your income, so if you go into investment banking you make \$150,000, you pay 5 percent. But if you just decide to go teach in an urban area and make \$30,000 you would also pay 5 percent, so in other words, you wouldn't find that doing something public service would be a huge burden, well, imagine if we said that when there is a very expensive technology out there, that anybody could borrow you know, could get the technology, but they had to pay a small percent, 5 percent of their income had to go to paying it back. Well, you know what? Some people would never pay it back. Some people never would, perhaps. But nonetheless, we would be freeing up the technology for hundreds of thousands of people who go to work. Many people would pay it back. As long as you have got the percentage small it would never be overly burdensome, and when people say well, how do you know that people aren't just going to misuse it? How do you know that everybody is not going to ask for the most expensive technology, well, if you have to pay back a percentage of your income even at 5 percent that is a pretty good argument. These are issues, maybe a great idea, that may be a bad idea, but that discussion ought to be happening. It ought to be happening. And he we ought to be showing for every Joe Martin or cHRISTOPHER rEEVES who is using technology to work and be productive, we ought to be showing somebody who is not, who can't afford that and asking how do we justify that morally, and how do we justify that economically, so I guess my message is, that there are many important arguments here, that I want to shift this argument into the national economic debate. I want to say this is part of building the workforce of the future. I wanted to say that when somebody is speaking, they should talk about dignity. They should talk about morality, they should talk about individual opportunity, but they should also talk about the national economic imperative, and people like myself should be charged at looking through every single government program and have one test. Does it in any way discourage people from working? And if it does, it should be fixed, and then it should be evaluated and if it is not working we ought to go back. But there ought to be a pro work incentive in anything, and if there is a government program which gives you more aid for not working, than for going to work, we ought to stand up and say, that just doesn't make sense on our values, that just doesn't make sense for our economy, so thank you very much.

## (Applause.)

MR. IMPARATO: Thank you very much Gene, I think we have time for 1 or 2 questions but we warrant to move into the next panel. I see Brian McDonald in the back of the book. Let's see if we can get you a mikephone.

>> This is Brian McDonald at the institute of disability in Oakland, to the issue of a national economic interest and I totally get that, and from your perspective, and background, I would like you to add some comments to this. I was speaking at the break with a colleague who I argued well to get where where you want to go it is a matter of political will, and the colleague said not quite right, it is a matter of political attention, we have this, no money, we have all of these problems in Washington. We can't go where you want to go. So as opposed to political will, how do you generate the political attention, and I say that with some background in the work on the ticket to work act. We dismantled, we were trying to dismantle SILOS across 5 jurisdictionness Congress, over 5 federal programs. We did not dismantle these SILOS. We did not have the comprehensive reform that we were after, and my case is to get to that level of reform you are looking at, you have to have required infrastructure reform between huge federal and state bureaucracies. That is an attention that we don't have today.

>> I think that discussion is a great one, and I think it is one that goes on in any form of movement. As I just said I work on an area getting US aid for education, in poor countries overseas, where you know, as I said, you know, the best -- the people got the best attention for us were the TALIBAN there was never more strategy that we had that got more people on the attention, but it is very important to understand this. And I want to -- I want to kind of paraphrase something that I heard president Clinton say with us, I was with him in OHA, at a US reform, and it was very contentious but he got up and he said something which was really powerful, and I think it applies here. He says, a lot of people in the MUSLIM world hate us because you think Americans hate you. And he said dislike you. And he said I want -- I'm not telling you to like us or dislike us. But I'm saying if you are going to dislike us, dislike us for the right reason. You shouldn't dislike us because we don't like you. You should dislike us if you want to dislike us, dislike us he said, because we don't know anything about you. We have never taken the time to learn anything about you. Americans don't have a bad opinion of most MUSLIMs or the MUSLIMreligion, we basically pre-9/11 had no opinion. Now that is an important way of confronting an issue because it means that you are not -- it is a recognition that you have a problem, but it is not that you have to overturn an obstacle of resistance. You do have have to grab the attention, and I think it is something that one has to learn. Now, in disability -- in poverty reduction, sadly, sadly, the single thing, this is a sad comment to make, next to 9/11 the single thick that has made the biggest difference is that the world's most famous rock star, BONA has dedicated his life to this. And I thought that is trite, and it is not trite, he gets in and talks to world leaders, he gets world attention he gets an hour of their time. Many of you thought that was a shame senator Brownback couldn't speak much. It wasn't a shame because let me tell you how the Congress office, a White House office goes, he doesn't just come here, he gets a briefing. He has to think about what he is going to say and what he is going to do. So when you get somebody like that to an event here it actually doesn't matter whether he speaks. You have already done something good. Somebody in his office had to brief him on your issues. He had to get up to speed. He had to think about what he was going to say, and he may have come here and said God I don't have much to say. And that is a man who may run for president of the United States on the Republican party. So I do think that you have to figure out what is the best strategy for if grabbing attention, I tell you, you know, Andy is very effective, and I will tell you part of the reason that I'm here, was because I was working on my book and I was in a desperate deadline and he was willing to drop everything he was doing to look at what I did. Now, you know, he may have had ulterior motives. He may have thought --

# (Laughter.)

Gene Sperling: I might get this guy to come back from Paris early in the states, but so there is a couple of things, I think that you do have to figure out ways of grabbing attention, and I do think, to be brutally honest, I think that there is two ways to do that. One, is to make it -- make yourself seem more powerful politically so that people have to pay attention, or to shift the way people are thinking about it which is a little bit more of what I was trying to do, to shift into a larger economic workforce issue. Every one of these politicians goes around and gives the speech about American workers but here is their points, science, education not enough kids are going into engineering. You know, when they are giving their 5 bullets and the fifth bullet every time starts being and we only have 37 percent of Americans with disabilities in the workforce, then you are going to start to be you know, getting places. So I think you need to figure out what the points are, and I think you have to be very practical about how you get things into the you know, into the political arena. When you are in the White House, the world is bombarding you. It is very hard, and I hate to say it but you start kind of looking at oh, the environmentalists want this oh, my God the civil rights groups want this, I'm for all of those causes. I'm a progressive but that is the way you start looking at things. I think you have got to try to put yourself in those -- in the people's shoes. You need to give people like myself how do you put yourself in their shoes? How do you tell them why in this bigstaff of things that are all important, this should go to the front of the staff, or you can do that. -- to the front of the stack, and some of it may be getting people's attention, for example somebody just coming to me and saying look, Gene, I know you are busy. I know it is crazy, but if you just call all of the government scientists together and told them the White House cares about this, you know, we could get something done. Well, what happens when you do that is I say okay fine. But then you learn something in those two hours and you say well maybe I'm going to work more, why haven't we done more on this thing? So I think that there is two things. One, I think you want to be seen as more politically powerful in the next election. That is kind of the part I hate the most, which is just being another kind of powerful so-called special interest group. But I think theother thing is to break out of that paradigm and start saying no, this is a Browder issue and I know Andy is waiting for me but I want to go back to the global poverty issue. One of the way way it is global poverty issue has done better besides the special interests group, they have less voters, but one of the things they broke into a different paradigm. This came about terrorism prevention, this came about how do we have a more peaceful world, it went from a little special interest of care, safe the children in OXVAN. It came to a bigger area oh, my God there are people being taught in school to hate us and despair in Africa. Part of this came from a political strategy with celebrities getting greater access but part of it came from a bigger

perspective. So how can you be more -- but how do you also start shifting into another Browder perspective, and I'm suggesting one, which is the national economic workforce PERSPECTIVE, and making this a national economic imperative.

MR. IMPARATO: Thank you very much. We are going to need to move right into the next panel, but please join me again in thanking Gene from coming back from Paris.

## (Applause.)

>> If I could have your attention, we are going to move into the -- I'm Karen Ignagni, we are going to pick up very nicely from where Gene Sperling left off. I think what he was talking about very persuasively was a little bit about the fact that when we talk about economic security in the country, when we talk about productivity, which are things that people are increasingly sometiming with why do we think about improving health care benefits and having them available, the issue of disability, disability coverage, and how we manage disability and coordinate care are normally not things that have risen to the top of the people's focus. And I think that this conference, hopefully, will begin a new focus a new effort in expanding the dialogue and beginning to expand those concepts of economic security, and productivity to include how we get people back to work, how we manage their disabilities, and how we do a better job overall. We are very excited that we think that the private sector can contribute to that, there are path braking things going on, my colleagues are going to be talking very specifically about all of those things, and a range of things. First I would be remiss on behalf of all of us if we didn't thank you Dorcas Hardy for her leadership here, her team, the policy committee, for her focus on disability.

### (Applause.)

KAREN IGNAGNI: I know everybody is singing Dorcas's praises but you can't do that too often as far as I'm concerned so she is a real leader and we thanks her for the focus, we had the opportunity not too long ago and many of you may have as well, to participate in a mini conference on long-term care, and there was a great deal of discussion at the mini conference on that issue about the need to discuss moving away from thinking in SILOS. And nowhere is that challenge more evident than in disability. Where there is best a lack of awareness and ate worst denial on the part of the public about the potential of becoming disabled, before we get to how do we improve the issue of coordinated care and all of those issues that go along with that.

Last year, we conducted a survey on disability. We found that there was a major disconnect as everyone in this room knows how the public assesses risk of disability, and the potential to become disabled. Each of you knows that 1 in 3 workers over the age of 30 will become disabled for at least three months at some point during their careers. And some never return to work. Think about that. 1 in 3 over the age of 30. But yet, nearly 50 percent of all Respondents said they weren't concerned about potential disability or illness which could keep them out of work for an extended period of time. And I think that there are some answers to shed light on why there is this disconnect. First, a substantial majority, 58 percent of working adults believe they are covered by disability insurance. But only about one-third of workers nationwide are in fact covered. I think can give you some personal testimony to this effect. I participated in a judging recently a national panel looking at employers that were doing the best for their workers. And as we looked at the spectrum of healthcare benefits, life insurance we looked also at disability. The committee was very focused on whether there was coverage available through the employers, and a number of these path breaking employers hadn't gotten to the disability issue so I think that focuses us on the attention and the issue and the explanation for some of the disconnects. To compound the problem, workers always overestimate their coverage. First of all, people think that they are covered by Worker's Compensation, so they don't need to think about short-term or long-term disability, yet everyone in this audience knows only about 10 percent of disabilitys are covered by Worker's Compensation. But 59 percent again a disconnect the survey believed that the portion is much higher. This gap in understanding about the need for disability income protection, is put in stark relief by the fact that many working Americans say that they could only sustain their families if they were to encounter a disability for three months or less.

So this makes it crucial in our view for families including families that depend on income of an aging baby boomer to understand the likelihood of disability, the nature of disability, and the need for disability security. We have been doing a number of things in addition to this survey. We have begun to investigate a number of partnerships that we will be talking about in the coming months leading up to the White House conference with key implorer groups. We have also reached out the a number of advocacy organizations and we want to expand that. I know a number of the key advocacy organizations are here today. We have had a very productive partnership with the countries Christopher Reeves foundation. And we anticipate that we are going to be joining with them -- I'm sorry for the voice, and a number of other organizations to do some conferencing around this issue as well. So we have a knowledge gap. We have a lack of not only information, but a lack of I think broad interest on the part of working individuals to actually reach out for this kind of protection, because they are not aware that they are not protected. In addition, we have much more we can do in how we manage disability, how we get people back to work, how we coordinate the care and how we take some of the concepts that have been path breaking in the health care arena this terms of disease management health care coordination, pride and dignity and bring it into the disability insurance experience and the disability management experience. And I'm delighted today to introduce two individuals who are at the front lines of this. And my colleagues. And before I do, on our parts, all of us in the private sector, not only to commend Dorcas Hardy for her leadership but I would like to sort of suggest -- I would like to suggest 3 take aways that we think would make this conference not only the most worthwhile experience but the conference could very strongly contribute to the national dialogue. First: We hope that a public private partnership can be forged out of this conference bringing all of the stakeholders from the advocacy community, the

employer community, the public sector, to the private sector, to join in an awareness campaign about the risks of disability and what we can do to make sure that more people get protected.

Number 2, we hope this conference and it is well on it's way can shed light to the many facets of this issue from one, income security, new techniques to manage disability drawing on the healthcare experience, and innovative back to work programs. And 3, we hope we can frame programs where we can bring these tools that have been developed and are being implemented in the private sector to the public sector programs, to assist in the management of that part of the continuum. So I think just as in health care, and a number of other issues, we are talking about private public partnerships. We think this issue lends itself to that. We think there is a number of things that we can do, and we can do together, and we are very excited about that. Two of my colleagues who are on the front lines of working on these issues, and making all of this happen, are Ron Leopold, and Ken Mitchell. Let me tell you about each of them, and I'm going to turn the microphone over to them. I also have to explain that I'm going to be exiting as in this case, stage left because Congress for all of you that deal with Congress they are trying to pack 6 months of work into now probably a little less than a week in terms of working numbers of days. So I have been summoned up to one of the key committees that is working on this issue, and on long-term care so I hope you will please excuse me and not find this disrespectful. You are in fine hands with my colleagues, so let me first introduce Ron. Ron Leopold, MD, MBA, MHH, is national medical director and vice president of MetLife disability. He is a board certified occupational medicine physician who holds a Master's in business administration, from the Wharton school of the university of Pennsylvania, and a Master's in public health from Boston university. He is an active member in the American college of occupational and environmental medicine, Dr. Leopold currently serves as clinical strategic leader for MetLife disability and has led development of the MetLife durations guideline and the clinical claims model triage model. Industry leadership, new product development, Ron is going to speak first and then Ken Mitchell did follow, he is vice president for corporate return to work programs, from uNUM Provident corporation, received his Ph.D. from Pennsylvania stateuniversity and served 7 years assistant and tenured associate professor in the School of Medicine at Chapel Hill. Dr. Mitchell has served as the director of rehabilitation for the Ohio industrial commission, president of national rehabilitation planners, and as the executive director of the international center for industry labor and rehabilitation. A private nonprofit research and educational group based in Columbus, Ohio. He is currently serving as vice president overseeing these programs for you numb Provident in Chattanooga Tennessee, so please -- they are in the front lines and you will be in fine hands with them, and I hope everybody will forgive me, and understand why I'm forced to go to Capitol Hill. When people call you must listen, so please join me in welcoming thing.

# (Applause.).

>> Good morning, my name is Ron Leopold I'm happy to be here on behalf of MetLife and happen to be here with my colleague Ken Mitchell from you anymore Provident. I'm aware that we have many perspectives here today and when I looked at the name cards I think we are all looking at one another's name cards it is so interesting to me especially not being a Washington insider to see all of the different organizations represented. And I wanted to share with you maybe point out my perspective. I think there is a lot of people in this room, that are saying, give this conference given disability, what are the consequence these we need to think about regarding aging? And I think that is a a valuable perspective, and certainly both my organization and Ken's organization are critically interested in making sure that people with functional impairments can find gainful employment, can return to gainful employment or enter.

There is a second perspective, and this is going to be the perspective that I'm going to talk about. It is a focus on the older worker, and that is, given work, and given the aging workforce, what are some of the disability challenges that we are all going to have to face? And so I want to talk about five things briefly. One is, I want to visually explore the magnitude of the age wave. And I will acknowledge this. I will be working from PowerPoint slides, my presentation is very visually oriented, so I wanted to acknowledge to those folks either with visual impairments or you guyness the cheap seats in the back, that I will do my best to describe what you are say seeing.

Second, I wanted to introduce some of the key drivers for why we in the baby boom generation will either have to stay at work or return to work. Third, I want to begin to address the natural prevalence, the natural incidence of chronic conditions in a population of people in their 60s, and in their 70s, and then finally, I wanted to talk about the financial imperatives some of the expense challenges specifically as it relates to paying for health care costs that boomers will face.

And finally, at the end I would like to give you 5 trends for all of us to think about. This is how it all started. The generation from 1946, to 1964. 78 million strong of a base of about 300Americans. 48 percent of American households have at least one baby boomer. I am a baby boomer. We have all been thinking about this population since it came on the scene in the late 40s. We have been or should have been preparing for this group, oldest member of which is 59, going to be turning 60, in 2006 to enter old old to enter the second or third part of life, to cross into age 60, 65, age 70, and beyond. I will tell you my friends that I feel that we are ill prepared. This is going to be a huge -- a huge change. 1990. I'm going to show you in just a second a sequence of population distributions. This is 15 years ago. On your left, the blue is men, on your right the TEAL is women, and it shows given age. The bottom bar is age 0. Going up through the 30s, 40s, 50s, centering up on 100. The red horizontal line is age 55. This is 15 years ago. Think about where you were 15 years ago. Not that long ago, although it seems like a long time ago. Many of the basics of today's modern life didn't exist in 1990. I will bet nobody in this room were dealing with e-mail, internet, cell phones, reality television.

(Laughter.)

Things were very different then, very simple. This is 15 years ago. Watch this. (Indicating) this is 20 years from now. I'm going to try and go back. 1990, 2025. This is what we are living today. This is the shape of our society. And in fact, if I go forward to 2050, we are transitions to a very different society. And quite frankly, I don't have it here, but the slide shows the year 2100, looks an awful lot like the year 2050. This is a look at the 3 snapshots. 1990, 2025, 2050. And I will tell you, I will tell you that this represents tremendous change. And this is going to touch upon everything, all aspects of our life. There is a huge the sheer magnitude of this is almost beyond comprehension. How is this going to change housing in America? Transportation, architecture, healthcare funding, healthcare delivery, city and community design, retail, media, popular culture? The sheer number of people over 65, and the sheer number of people over 85 is going to grow dramatically.

In 2020, there will be 45 percent more Americans over 65 than there are today. Those numbers are huge. That is 78 million that we are talking about are crossing an important threshold, and most of my comments today are going to be to think about that. My grandfather was a farm may sift in HADEN heights New Jersey, my grandmother worked in the store with them and they had worked there and worked Leopold's pharmacy since the 1930s. At age 65, he properly sold the store, and retired. They drove across the country in their TEAL blue Oldsmobile, and sent me postcards from the lower 48. He turned 65, sold the store, retired and went. When I was a kid, this is true -- I thought you had to retire at age 65. I thought it was the law. And the fact of the matter is, a retirement age of 65, isn't an anachronism. It started in Europe -- in Germany under BISMARK's rule to establish a pension age which back in the 1880s made pretty good sense. Today the prospect of a 65-year old retiring is very different. Today 65, is very different than the 65 year olds that any of us grew up with. This is not your grandfather's OLDSMOBILE. In fact we know that older Americans will need to stay in the workforce, and that is really the perspective that I want to address today.

What happens when a cohort of individuals in their late '60s, in their 70s, stay or return to the workforce? We have been hearing about -- we heard from Gene Sperling about a worker shortage and I will address that in just a moment. But let's be clear that we as a society, for a number of reasons are going to be -- are going to have to accommodate a growing number of people. It will be good for our economy. It will be good for those individuals, but we are all going to have to learn to think a little bit different. Why are people delaying retirement, and why are people today as they think about being age 68, age 71, planning to stay in some mode of the workforce? Four reasons. Good. Good. Bad, bad. Greater longevity, that is good. More vibrance, also good. Inadequate savings, bad, and greater expenses, specifically healthcare expenses, a challenge. Let's address each one, longevity. Americans are living longer and healthier lives, half of all 65-year old men today will live past 85, and 1 in 4 will live past 92. Those numbers are significantly greater for women. Today it is very common for a person in their 70s, to be a caretaker for their parents. You heard of the sandwich generation we are beginning to hear the term the club sandwich generation.

# (Laughter.)

>> My mother is 72, my grandmother is 94, they haven't crossed the caretaker age but my mother still has to concern herself with the lively head. Of course in my grandmother's case she is out playing cards all the time, playing bridge you can't keep track of her. But the fact of the matter is it is very common for folks today in their 70s, to be concerned with their parents and we are going to be seeing more of that. So the idea of a club sandwich generation really does again -- really does begin to illustrate some of the changes. Older workers, perspective older workers, bring a lot of positive attributes to the workforce, they bring knowledge, maturity, experience, organizational memory if they stay in the workplace at an employer, cultural memory, diversity and a strong work ethic. Today 72 year old, today 68 year old, typically has healthier life styles, is healthier than their counterparts 30 and 40 years ago, generally has healthier habits, reduced rates of smoking and are much more active physically and mentally than was the case 30 or 40 years ago. The challenge, however, is that today's - the generation that is entering retirement today, who we call the silent generation and then the baby boomers, who are fastly piling up behind them had grossly underprepared for retirement. Given longevity, and given rising expenses, this is going to be a major problem. I am showing a graph from MetLife's employee benefits trend study. And the headline here, is that retirement planning is really poor across all age groups. In the group, 51 to 60 years old, for instance, only 28 percent of these individuals Wednesday polled said yes, I have achieved or am on track for achieving my goal for retirement. Add to that, that people in general underestimate how much money they are going to need to sail through older age. These number, I believe, are staggering, and they are worrisome, and if anything, they should motivate all of us in this room to think about how can we make a workplace more accommodating to an older generation that is going to have to lively income up and above the traditional sources such as Social Security. We are going to have a huge supply of folks in their late 60s, and early 70s, that are going to want to work. Increased supply, the good news, there is going to be increased demand. You heard Gene Sperling talk about worker shortage, by 2010, five years from now, according to the US bureau of labor statistics American businesses will face a labor shortage of more than 10 million workers. The good news is that American employers are already anticipating this new supply of labor and talent. I know we have some friends here from the AARP, and we know that many of -- the AARP has been very proactive in promoting and recognizing employers that have actively engaged in recruiting, attracting, and maintaining older workers. In fact, they selected 13 of which we are very proud that MetLife has won.

We know that in our -- as we poll employers, we know that employers especially larger employers recognize that they are going to have to create a workforce that is far more attractive to people in their late 60s, and early 70s, and I will give you the example of one of those 13 company, Home Depot. And I use this as an example because I think that most of us have some level of familiarity. My take on them, and what Home Depot has said, we are going to create a workplace that is attractive for older workers. Think about a Home Depot experience. You have some kind of a problem at home. Some kind of CAULKING,

plumbing, electric drywall thing, obviously I'm not one of their more savvy customers, you have a problem that you need to fix. You walk in, and you find an associate who will hopefully understand your problem and be able to find the solutions. Well, that is really somebody who has a lot of knowledge, and somebody who has a lot of training. It makes great sense for a Home Depot to say, we have a lot of men and women in their late 60s, early 70s, who have seen it all. We can train them on some of the new technologies. But as we look at our job design, if we look at how we are going to accommodate workers, if we are looking at perhaps part-time and flex time arrangements, we can take a leadership role in the future by attracting -- by attracting workers in their 60s. We know we are all going to be facing a worker shortage, we know that the quality of our sales associates, and sales personnel are critical to the success of our program. I salute and congratulate Home Depot on that.

Positive and negative. I had said before, good, good, bad, bad. The good. Folks are living longer. They are going to be more in their 60, and 70s, this he are going to be more vibrant. They are going to want to work, and fortunately, employers are going to need good workers to come on board. The downside is, people will have inadequate savings, greater health care expenses, and most notably when you look at a population of people between 65, and 75, you are going to see greater rates of chronic conditions. And in fact, most recent medical studies that are looking macroscopically at health care costs, are focusing on chronic conditions as a major driver of those costs. And so we know that employers, we know that Medicare, we know that all sources of funding of medical costs really needs to concern themselvess with the growing numbers -- and this graph here shows from 1995, to 2050, the projected raw numbers of people with chronic conditions. Why is it growing? It is growing because it will grow because of an aging workforce.

These are some of the conditions that we see in a population over 65. This is a CDC data, and again, if we are talking about an older population, a more vibrant population, that is great. But let's also recognize the older a population, the greater the demand for healthcare services because of the prevalence of the conditions that you see here. As a result, an older population is often more expensive when it comes to healthcare funding. And that is going to be a concern for all of us. This is a graph of data from the society of actuaries. What is the expected rate of long-term absence from work, long-term disability. Having to be out of work for more than 6 months as a result of a medical condition. And what we can see, is that this rate increases dramatically as you go from age 45 up to age 65. The reality is, the older we get, the more apt we are to develop a medical condition, that is going to preclude us from getting the gainful employment, from earning the income that we are going to increasingly need. Also CDC data that just speaks to in men and women, the prevalence of functional challenges in a population over 65. Chronic conditions, and functional challenges. When Home Depot looks at hiring a cohort of people 68 to 72, they may need to revisit what are the lifting requirements? They may need to revisit, what are the climbing, crouching, and stooping requirements for those associates. And they will, because the wing strategy is going to be to create a workplace that act dates these people.

There are three conditions that I'm concerned with mostly with regards to working population crossing beyond 65. First is heart disease in the workplace. More than 70 million Americans, over 1 fourth of the population live with some level of cardiovascular disease. The big ones are coronary heart disease, hypertension, coronary artery disease, and stroke. Coronary heart disease is listed as a leading cause of premature permanent disability in the US workforce and the economic impact of these diseases on the healthcare system continues to grow projected to be 395 billion this year taking into account healthcare expenditures, and disability. Arthritis in the workplace. What are the physical requirements at a food services establishment. In inventory and stocking. Or rather 10 years ago there were 40 million Americans with arthritis. 15 years from now there will be 60 million Americans with arthritis. And then finally, cancer. Cancer is basically a disease of aging tissue. 9 of the 10 leading causes of cancer increased with age, and that increase rises dramatically after age 55. Nowhere, nowhere is there a set of medical conditions where we both public policy, as well as private policy, can do so much with regards to prevention and early detection to prevent, to prevent premature death. To prevent long-term disability, and to prevent people from not being able to earn their living. Early retirement for the lucky few. A study by the employee benefits research institute shows that a 55 year old retire rye today will need 83,000 dollars to cover typical group insurance premiums plus out-of-pocket expenses for 10 years just to make it to age 65 when Medicare kicks in. The amount needed for 10ers I don't of individual coverage, is even higher at 256,000. What we are actually looking at is an era of fading retirement. We have older Americans, those older Americans will need to work. They will have greater prevalence of disease, and the last piece I would like to explore is health care costs.

What will Medicare pay for? This is a nice depiction of what Medicare paid for in 2001. We heard earlier today about the Medicare modernization act, and so the playing field is changing. However, it is not changing so much that the health care burdens, the healthcare challenges for people, especially middle and lower socioeconomic groups won't have significant challenges with healthcare costs. Out-of-pocket health care expenditures is increasing. It is increasing for all Americans. It is increasing for all working Americans. And it is also increasing for all Americans over age 65. This graph contrasts 1997 to 2001. Since 2001, we have experienced couple digit healthcare inflation in all sectors. We talk about Social Security benefits which I have here. Social Security benefits. This graphs what is the source or projected sources of income for a population over age 65, based on whether you are in the highest fifth of income, fourth, third, second and first, and what we find is that for the majority of Americans, more than half of their income protection, more than half of their income will come from Social Security. The challenge is, in addition to this, what are the healthcare costs that you are going to have to endure? We are all talking about, thinking about Social Security benefits, and whether or not the security of those benefits will remain. How competent are we that any of us will get the same benefits that folks are getting today. Add to that, add to that, the huge burden, a burden that really has not been in my opinion adequately addressed in the press, a huge burden of dollars for Medicare.

A of 5 year old without employer coverage would need at least 116,000 dollars for Medicare supplement and drug coverage through age 80 according to the employer benefits research institute. I'm running out of time. I would like to run through very quickly biotrends, give you concluding thoughts and hand it off to Ken Mitchell. Trend number 1. The SURFIN life. Gray geeks define a new trend in the over 60 set. The web and beyond become a part of daily routine for the majority of older Americans, older Americans define the leading edge of medical consumerism, paving the way how much information is packaged and consumed. Gray worker benefits, gray employee benefits. Employers, such as Home Depot, seeking to attract the increasingly desirable older worker will pioneer new benefits designed such as senior sign on bonus, extend part-time opportunities with streamlined benefits. And we will see a proliferation of Medicare MEDIGAP benefits. Flower power era 2. A renewed appetite for alternative and complementary medicine, new old hip pies defined a mind-set renaissance, as the flower power generation grabs the last third of life on its own terms. Bioimmediate, technical bonanza, improved ability to forecast individual medicical futures leads to better prevention and early detection of important diseases in an older working population such as cancer, Alzheimer's and Parkinson's. Targeted treatments with unprecedented efficacy. However, this technology comes at a cost creating even greater medical expenses. And then finally, a new senior activism, senior unions forming beyond right to work advocacy more than the gray panthers we saw back in the 60s, and '70s, and defined new areas of work and less sure for older Americans to participate in. Some closing thoughts before I hand it over to Dr. Mitchell. I do believe the challenges here are greater than any of us had imagined. The magnitude of this demographic shift is COLOSSAL. We do have new opportunities. It is a new type of workforce that we can leverage, opportunities for prevention and early detection to offset future medical costs. Policy changes INSENT employment of older workers, and I believe this is an imperative. So that those who want to work, those who can work, and those who need to work are given the opportunity to find gainful fulfilling productivity work and employment. Thank you very much.

### (Applause.)

KENNETH MITCHELL: Just to compliment the brilliance of our planning group. They have positioned me just before lunch, and I have never missed a lunch in my life. So don't go away. We will get done on time, I guarantee you. I have perfected this 45-minute presentation into 12-and-a-half minute, and we should not have at all a problem. Except for the computer that doesn't work. I hope you understand you have 100 people looking at you right now. I think I messed up his concentration. One of the goals this I will have for my presentation I want to put a face on the age and disability issue. You any Provident corporation has one of the largest databases outside of the Social Security that looks at lost time and disability, and my program merely begins to present that face and the issues that need to be involved, my particular role at the organization is simply this: Although it is a simple task, it is not an easy task. It is my role is to help employers to build a corporate culture and practices that keep people at work, and return people to work. And so within that simple mission, in terms of directness, we work with all of the complex vagaries of the corporate politics to begin to influence and drive whether a person first of all is considered employable to how they work with impairments, and then what happens is some type of illness or injury begins to create a problem in their ability to perform their job.

And what we will share with you is some of the profiles that we feel are in critical in moving things forward in establishing the types of programs and the type of services that are necessary. Also, I just want to bring to your attention, that on the outside here in the hallway, we have a new MONOGRAPH being prepared for this particular program on the aging WORKFORCE, and it allows us to understand not only the data but the opportunity that are needed to move forward.

>> I hope we can get this fixed shortly and eye expect that we can. I want to expedite matters letting you know know that we set lunch straight down the hall and we have an hour for lunch, and we have a luncheon speaker. So after Dr. Mitchell's 12-and-a-half minutes, we will move people over, and get seated and get started and we can move on with our speaker. So okay. Thank you.

KENNETH MITCHELL: I think it is important that as we begin this, that for those of you that wonder why you are here, or what the interests are, my sense is that if you remember who Annette and franky are, then you know that you should be here. If you know who HOWDY, DOODY is here then you know why you are here, and those of you who had sunny and CHER as the cultural icons, these are the people that we grew up with at the leading edge of the boomer generation, these are the folks that we grew up with, and all of the factors that are going to be involved. And so let me begin my presentation, really, with the idea of quoting one of the seminal comment, or seminal move veries of our boomer generation, and that is the graduate. In terms of Ben when he is at his graduation party and one of the family members comes up to him, and basically says, plastics. Well, you heard it here today. Well, plastics is not the word we need to be focusing on. We need to be able to focus on the word productive aging. Productive aging is going to be the future of not only the generation, but as we work with employers, as we work with individuals, and coming to grips with the health care and performance, and impairment, and benefit issues, the notion of the idea of productive aging, is a theme that we are inviting our corporate customers, large or small, whatever industry, to begin to establish a process of maintaining and protecting the productivity of the individual, especially after the age of 45, and 50, through retirement. Because we are going to see that the retirement is going to be as Ron mentioned, is going to be extended and we are not going to see cliff retirements anymore, where someone goes and stops working. We are going to see return to work, and stay at work, and incremental adjustments to this particular activity.

(Applause.)

KENNETH MITCHELL: Thank you very much. The principles of productive aging. From my standpoint and from our organizations standpoint these are the 3 elements that we would like to share with you today that we hope you take home and begin to create and understand that we are trying to help employers from the front line of having them build policies and practices that make a difference in protecting their employees. First and foremost we understand that age is not a disability. And aging is not a disease. Obviously, age and aging does have implications, but when we convert these to these type assumptions, we end in trouble in trying to help employers to build and keep the productivity going, impairment does not equal disability. This is something that we have to struggle with in terms of the terminology, the vocabulary of this group, and we live in a world of medical evidence, and medical insurance, and disability insurance, and there are thresholds where we have definitions if you are impaired but may not be disabled, if you are able to function and work, and continue on, and you are unable, and you are unable to be able to do those things, then you meet certain entitlement areas, certain eligibility program, but on the whole the productive aging model impairment does not equal disability, but age and disability present work health and life predicaments that need to be anticipated, avoided, and certainly solved.

We have been talking about aging with a disability, aging to a disability. We have had some great intro ducts of aging with a disability this morning, that Ms. Hardy provided and was able to present a clear picture for us, but on the right side of the slide we talk about the aging to disability, and these are the areas that we need to be paying attention to, is that injury and chronic disease are most common in this particular grou, when we talk to our employers there are 3 basic elements that they are concerned about, healthcare costs. Where we might have a disability cost of 1 million, the healthcare cost bill may be \$10 million. And so from that standpoint, the administrative and financial burden of employers to deal with benefits, is going to have a striking and effective way of changing the benefit world. And so employers are going to be taking that into consideration. And these are the type of patterns that we see. Musculoskeletal clearly is the greatest impact on the performance of work and ability to work within this particular group of individuals, these are individuals age 40, to 60. Cancer number 2, 17 percent, circulatory and 18 percent behavioral health at 7 percent, we will see some changes over time, ought about it is important to talk about musculoskeletal disorders and impairments is that they can be accommodating. And that is an important issue that employers have to understand, within those accommodations, they are able to keep people at work, eliminating the need for them to go off of work, and then to bring them back in a timely effective way, lost time incidence, we see that short-term disability in the older population goes down, but long-term disability goes up. When a person does go off work, at the age of 40 they tend to stay off work longer, learning new skills, you heard that comment, that old dogs can't learn new tricks. That is not true. It depends on the dog and the trick. The older person when they have to go through a learning process, they obviously have learned it before, and what they get annoyed with is that you ask them to do something again. And the fact that this he are not learning is not a factor of not having the ability to learn but the choices that they just don't want to go through this again. This is sort of a wisdom that goes on that understand that this stuff is not necessary, and we need to move on.

Physical endurance. We know that from studies and research suggestions that physical endurance is affected. That physically, in terms of repetition, the strength is affected. It is a reality. Environmental conditions. Those of us that are getting older don't do so well in hot situations, hot environments. In terms of job satisfaction, the reports are clear, that the older worker has higher job satisfaction than a younger worker. But their job satisfactions are different, what are some of the different things we need to pay attention in the group, financial security post work it is the same of people -- access to health care, both for the same groups.

This particular slide represents uNUM Provident's experience in the LTD world and the reason we show this it simply talks to us about the risk in the disability insurance business of long-term disability in the older population. Now, you will notice-differences between Ron's and the act you the ACTUARIAL data. Ours is significantly lower, what that really represent sincere prospective LTD. And the sense is what we are showing the age workforce that group is diminished in terms of its numbers in the picture and this will grow, we see that this group and the 60 plus will be the growth industry in terms of long-term disability, and we as a long-term disability carrier need to pay attention to that.

In terms of when a person does go off work, age does make a difference. We see a significant difference when a person that is 60 years old goes off work on short-term disability, and then under 40 years old, and you can see it is almost 15 to 20 days per claim that that older worker stays off work longer. Now what is the reason for that? Is that a healing process? Is it a corporate policy or is it the medical community, the physicians play an important part in in process, because oftentimes they have a bias in terms of how they treat, and how they guide getting a person back to work.

And this particular study will show that most long-term impairments as you can see there are not too many may turn any tie impairmentness the over 40 group, we would expect that obviously, but we talk about cancer, and you talk about back and accident, and you can see this is consistent with Ron's data, and we must pay attention to the nature of lost time. Accidents, musculoskeletal, easily adaptable, easily accommodated by the workplace, we want employers to create the opportunity to have a flexible work site. Many years ago I worked in a research project at the university of North Carolina with the text tile industry. And what we found is we had a high incidence of arthritis, and we tried to predict what type of impact the type of disease had on work capacity. And what we found out there, is that disease did not have an impact on whether a person was working on not. And why? Well, what we found is we had a lot of people with a lot of disease that were working, and a lot of people with no disease or minimal disease that weren't. What was the best predictor of working with arthritis? It wasn't disease. It was the flexibility of the work site. The ability to adapt the work site to a particular impairment of that individual. In cancer. We have to be very conscious of the termthat is not used much, but is it a very critical one and that is the iatrogenic disability. IATROGENIC. Thank you very much. Iatrogenic disability, means treatment induced disability. Cancer treatment,

chemotherapy, disabilities the person, we need to have corporate policies and benefit plans that recognize that. That when a person doesn't have to expend certain types of benefits to go off the job or stay off the job to respond to the ups and downs and the cycle nature impact of chemotherapy. It is an important benefit issue that you have to pay attention to, there are many people that are on chemotherapy that need and want to work as part of the treatment. Industries. What industry needs to be paying attention to long time and disability within the WORKFORCE for the older worker, here are the top 4. Manufacturing, transportation, education, and healthcare. We put banking in because we thought we would put something a group that is not such an average older worker, but healthcare and manufacturing are typically the oldest group in here you can see that musculoskeletal inches are the highest for manufacturing and healthcare, other metabolic diseases diabetes, and other conditions related to this, this gives a sense that lost time disability, healthcare cost can be very industry specific, and we need to pay attention to those industries to move things forward. Now, the politics of incapacity, I love that term because politics deals with your self-interest. And that is what we are trying to do is look at the self-interest related to lost time, and when we talk to employers, we ask them, what are your self-interest? And here are a few. First of all, how do we define disability? The federal guidelines have 67 different federal definitions of disability for disabled people, very confusing. We into Ed to create a process by which we understand disability as a functional term, not just as necessarily words. Definitions and applications of age, age is important, but age expectations are very important, we are seeing great research and effort in the literature that suggests that today's 65 year old is looking more like the 55 year old 20 years ago. We expect that 85 year old in 5 or 10 years will start looking like the 65 year old today, because of medical well-being and all the things that go along with that. MORPHING benefits, we have to make benefits from a corporate standpoint portable because we are not going to have people staying at the same place for 35 years, people are moving, people are going and coming. We have to deal with that portability issue. Work to retirement transitions, I mentioned this is my opening comments that we ar seeing many companies looking at incremental adjustments to transitions back and forth, multiple careers, multiple opportunities go and come within a work site. Flexibility to work site accommodation sincere the critical need that we have to build into both benefits, as well as operations at the work site. The CAREGIVERS paradox. CAREGIVERS are very critical. But they the effect and disrupt productivity in the workplace because at the are not there or are moving back and forth, we recently did an family medical leave study and we find below 10 percent of the population that took family medical leave for caregiver responsibilities ended up with their own short-term disability or Workers' Comp claim within 6 months after coming off that leave. There is a connection in that area. And we need to pay attention to that. Cost of healthcare insurance and access to income protection is critical because the employers are looking for a creative ways of reducing costs and making benefits accessible so voluntary benefits are important aspect of offering that benefit. Where the employee pays for it the employer gives the opportunity to give this. Unfortunately, one of the consequences of that is people roll the DICE and they don't accept it don't take it because they think it is too expensive or don't need it and they end up in a real predicament. Here is a very important study when we talk about healthcare cost it is a multi tiered illustration of the impact of healthcare cost by age as you can see in the blew charts in the front the blew bars in front we are basically looking at the impact of age on healthcare cost. That is people at low risk and you can see there is about a 25 to 35 percent increase in healthcare costs by decade that has reported in this very large employer research group. Put out by the inch inch of Michigan. What is important is look on the on the back side where you have this individual when you attach risk factors to the age, you get a 300 to 400 percent increase. So risk factors make a difference. Aging ask make a difference, but keeping that aging worker healthy, free of diabetes, free of smoking free of high cholesterol in a way that allows them to maintain the nature of -- reduce the chronic disease are important. Because we look at the research that the employers are telling us, healthcare cost is a number 1 concern. Lost time is number 2, and the third one is a term called present teaism, that is when the person is at work, but can't perform because of a chronic health problem, maybe depression, diabetes or other forms of distracting their ability to perform, so those become the burdens of th healthcare. This slide present good things to support that. In the development we are going to be talking about social engagement and productive aging, two important things, they are very, very connected, in a sense we see increased social engagement, we see improvements in ADL. We see improvements in the OVERall ability for the individual to have a higher life satisfaction, and have a less degree of disablement by functional improvement. So the ability to be socially involved and engaged is show shown to have a definite impact on the physical side, the remainder of these are capable of explaining, and underlying the nature of this connection that we are going to go into great deal of exploration in our discussion group and the social engagement and productive aging area, now here is the challenge that the private sector has and I would like to conclude with these, one is the private sector the employer has to protect the work capacity of the worker. If they don't do that they are going to be challenged by a growing number of individuals looking to be on disability, that won't have the opportunity to pass that threshold because of certain eligibility, and certain benefit packages. We have to be prepared to prevent, and ameliorate the nature of chronic disease in the WORKFORCE. we need to avoid isolating that individual by having them move off work so they don't have access to friends family and peers that they gain their ability to remain hopeful. And the final concern with the private sector we have to maintain a WORKFORCE that sees ongoing productive aging as possible. One of the things that we know about aging the degree of hopefulness of a better day tomorrow, is very critical, whether enthe hope is taken away from the employment status from a peer standing, and there is isolation, that turns into hopelessness and we end up with a much more significant problem, then our challenge over the next day is to have points of action from that public partner, public and private partnership, and here are five or six areas that we intend to explore very closely. One is what kind of incentives can be offered to employers to hire and retain individuals with impairments? How do we protect the work capacity? How do we engage the physician, and the employee in a partnership to maintain that person's functional ability and their over Al health. Employer medical cost relief that has to be solved. If not the burden of the benefit cost, the burden of healthcare is going to be so significant on employers, that they will make decisions that will have an effect not on only the productivity but employment opportunities, retirement benefits that is already beginning. We want to be able to explore how we can maintain and support the notion of aligning retirement benefits that support productive aging on

through full withdrawal from the workforce. And then finally, we need to explore the challenges and the opportunity to create portability of benefits because as the benefits goes, people will work, continue to work in a way that allows them to first of all get good healthcare, to protect themselves economically, so that they are able to put their best forward to maintain that productivity that the American workforce is going to be needing, and as we say in Chattanooga, it is time to get pacific. So what we want to do is we want to invite you to take now what we have shared this morning, and what will be shared in the he are search PANEL THIS afternoon, and let's get pacific about the ideas of how we can deal with not plastics, but productive aging, thank you very much.

### (Applause.)

WINTHROP CASHDOLLAR: Thank you very much. We have lunch in the next room. It is just a little bit down the hall, and we have kind of a very important an interesting speaker so I would like to encourage people to go ahead and make themselves comfortable in the lunch area, and come over. See YOU THERE in a few.

(luncheon recess.)

ladies and gentlemen if you would kindly take your seats to that we can begin.

JENNIFER KELLER: I think we will go ahead and get started. We have a full afternoon. Thank you very much. I'm Jennifer she high with the Department of Education, and I am very honored that I have if privilege to introduce my boss this afternoon, as anybody who introduces his or her boss knows it is a nerve wracking situation, and welcome to the panel on the New Freedom Initiative in action, assistant secretary John Hager was nominated by President Bush and confirmed by the senate in November of 2004 as assistant secretary of the office of special education and rehabilitative services in the Department of Education, prior to his appointment Mr. Hager was the director of Virginians homeland security with governor James gILMORE and governor Mark Warner, Mr. Hager was elected to lieutenant governor of Virginia in 1997 where he was a strong proponent of better improved transportation and more effective and improved government, and he received recognition as chairman of the disability division. He has mechanical engineering degree from per due and MBA from hair Harvard and had -- he was executive vice president of American tobacco company and senior vice president of specialty products after he had a near fatal bought of POLIO. As you can see, Mr. Hager is the perfect person to lead our programs, in the office of special Ed and rehab services. As a successful business executive, who knows the importance of hiring qualified individuals, whether or not they have a disability, and the role of education in future WORKFORCE development, as a successful statesman, he knows the importance of state activities, and he understand the challenges of our state grantees and the results that you can have at that level. And as a person who manages a disability to come back to a second rise in business, as an executive, he knows personally the value of rehabilitation and independent living programs to individuals and to the country. Please join me in welcomeing, Mr. Hager.

(Applause.)

JOHN HAGER: Jennifer, thank you very much. Obviously, she did it just the way I told her.

(Laughter.)

JOHN HAGER: She did a great job, and Jennifer does do a great job in everything she does. We are so excited now that she is serving as the acting dep tie commissioner at the rehabilitation services administration, and she has got a greet resume behind her work here at this conference, and so many other conferences where you see Jennifer. Thank you, Jennifer. We are pleased to get going with this panel because we were running a little late. But we will try to keep the wheels on time here. This panel has an exciting type. The New Freedom Initiative in action. Next steps in promoting community living. And as you know, community living, has so much to do with how people function, and it is integral and central to the planning of this conference to deal with aging and people with disabilities. As you know, the NFI is also central to the administration's efforts to improve the lives and opportunities of people with disabilities, and to participate fully in their American way, and American lives. And I'm delighted to lead the office of special education and rehabilitation services because we are so involved in so much of what the NFI is all about.

We are going to give a little update here as I'm the first presenter on on OSERs, before that I want to introduce the panel members, and amongst us we have shared interests and goals. And it is an outstanding panel and I'm pleased to serve with them today, first is Dr. ROY Grizzard, he was nominated by President Bush to be the first assistant secretary for disability employment policy at the Department of Labor confirmed in July of 2002. He is responsible for advising the secretary on issues related to the employment of people with disabilities, and to provide leadership in the department's efforts to increase employment opportunities for adults and youths with disabilities. Prior to this job, Roy served for six years as the economics near for the Virginia Department of Blind and visually impaired, our second presenter is Madhulika Agarwal, she is is here for Gordon man field today who was unable to be with us, and she brings great credentials she is the MTH chief officer of the office of patient care services at the Veterans health administration. In this capacity she serves as the principal advisor to the under secretary of health and Veterans health on policy matters and issues that relate to patient care and clinical services. DR. AGARWAL received her medical degree from RASTA university in en-Diane and internal medicine at VA center in Georgetown, in Washington, she also completed her masters in public health at George Washington. Our next responder is Ginny Thornburg who we all know who serves as the director of religion and disability programs for the national organization ondown. For the past 35 years, Miss Thornburg has worked tirelessly as a successful and highly regarded advocate for people with disabilities.

She co-authored and edited the award wing publication, that all may worship in its 7th printing and from barriers to bridges a guide to community action, as well as the ADA and the religious community. And our fifth presenter is a good friend John Lancaster, executive director of the national council on independent living which is the oldest disability organization run by and for people with disabilities. Since 1974, he has worked as a civil rights attorney on issues related to the integration empowerment of people with disabilities including serving as the executive director of the president's committee on employing people with disabilities under the Clinton administration, John is also a veteran of the Vietnam war where he commanded an marine infantry platoon and earning the purple heart and bronze star '68, so please welcome my distinguished panel.

### (Applause.)

Before we start with the panel I want to take a few minutes and bring everybody up-to-date on the work at OSERS which supports all 4 pill Larries of the president's New Freedom Initiative. We will highlight, you know, I'm going to skip through some of the details so that we can catch up time wiz but I want to highlight some of the major accomplishments and what we do at OSERS that relates to NFI since at OSERS we deal with people of all ages, from birth all the way through aging. We are responsible for programs that allow people who are aging with disabilities the support they need to stand their own. I think that is very key to age in place, so to speak, and to retain employment for as long as they want to, or need to, and in many cases, as you know, they are linked together. In order to achieve their own personal and financial goals. Although we are the agency that drives special education and deals a lot with youth with disabilities, we also through our RSA, and NIDRR functions deal in the arena that we are focused on, we are very involved with 3 of the four pill Larries that relate today to the conference, of the NFI. PILLAR 1 is increasing access to technology, and we do that at OSERS through our state assistive technology program, and the research related to that, OSERS contributes to this goal of increasing access of technology through the state AT act program, which is administered by RSA, and through its investment in NIDRR funded research.

The president recognizes that assistive, and universally designed technology can be a powerful tool for so many millions of Americans with disabilities. Dramatically not only improving the quality of their life, but the ability to age, and age with disability in later life, and stay in place. The president recognizes that barriers exist to the acquisition of technology, and thus the assistive technology act signed in October of 2004 is designed through the management of 56 statewide and territorial programs to assist states that assist individuals in accessing AT services. We also have alternative financing programs in 31 states, and telework programs in 20 states that provide loans to individuals with disabilities to purchase equipment that increases their employment opportunity by enabling them to work at home. The state AT act conducting public awareness activities, and one of the things we are focused on today is information about loans, about acquiring less expensive, or free assistive technology for recycling programs to loan programs, through many types of model programs that are currently blossoming around the country. It makes so much sense to take medical equipment or assistive technology and reuse it. People out grow it. People pass on. People no longer need it. People want to get the newest version, there's so many reasons to have lots of assistive technology equipment that theoretically doesn't have a home, that can be brought in, sanitized, reworked, and put in the hands of someone that can use it very well. So we are proud of our iniatives in that area, and also in the loan program area. And since 2001, NIDRR has funded over 85 million dollars in new awards for research to improve the independence, employment, community participation, and health of adults of all ages with disabilities. President Bush designated NIDRR's rehabilitation research and engineering program, RERC, as one worthy of expansion and significantly increased the RERC budget by \$6 million in 2001, and we followed up on that ever since. Currently NIDRR funds a total of 21 RERCs for a total program investment of \$20 million per year. The RERC's have provided many significant products that some examples include providing critical expertise in leadership in the development of voluntary standards that industry uses for wheelchairs, for restraint systems, telecommunication devices, information technologies, and technology over the worldwide web access. The RERC's led to the evolution of universal design, and has been so actively involved in a lot of areas. So we have got the loan program, the AT program at the states, encourageing the recycling program and the research that backs up so much of not just durable medical equipment and assistive devices, but life-style for adults.

Similar too, is improving education and we are obviously very involved in that through special education, but I don't have enough time today to really get into that, and it relates primarily to youth, as opposed to the adult population. PILLAR 3 is integrating Americans with disabilities into the workforce, and you are going to hear more about that from Roy in a minute, but doing a better job of maintaining employment for adults agingwith long-term disabilities is critical to developing a strong future WORKFORCE in securing our nation's competitive and leading in the global economy. Our people need jobs, but industry needs our people and the workplace needs people with disabilities to fill out so many jobs that are not being used. Lots of times it is a matching problem, or a problem of proper training and skills with this rapidly changing society and economy.

But I think more and more companies are learning to accommodate and retain employees as they age and acquire disabilities, and are realizing how good those employees are. According to the February of 2004 DOS employment projections the labor force will continue to age with the number of workers 55 and older projected to grow by almost 50 percent. 4 times the 1 percent growth for the overall labor force, so the assistive technology, and rehab programs all play a role in matching up this demand or this need with our supply. Another labor market trend to benefit people with disabilities articulated in this great book if world is flat, Tom Friedman demonstrates that technology and other developments are levellin the competitive playing field for all. People are just as used to doing business virtually without geographic distinction, without distinction of disability, without distinction of anything but skill and capability whoever and wherever the employee is. The president secured \$20 million in the 2002 budget in matching telework grants. The RSA administers this one, and we continue to make awards and to meet the needs

of employers as their WORKFORCE age RSA has joined force with the state VOC rehab directors to build an on line network just this year of employment specialists. These are single points of contact in a state to address employer requests for qualified job candidates with disabilities, and to act as a nationwide resource for information and referral regarding workers and job seekers with disabilities. So we are very active in the workplace arena, and I'm going to let Roy cover more of that. And finally. PARTICIPANT: PILLAR 4 the New Freedom Initiative is promoting full access to community life. People with disabilities rely on resources at the local level to help them maintain their homes in the community. Our independent living system, which John Lancaster will share information about, offers that community based support. In 2004, more than 215,000 individuals with disabilities benefited from the centers for independent living program, which is an increase in one year of 15,000 over the year before. A significant percentage of NIDRR's annual investment in research, and capacity building is dedicated to advancing knowledge, and contributing evidence based strategies that support independence, and aging in place, and increased opportunities for participation in community living. This is a program of over 100 million dollars per year. Some examples are personal assistance services, the center at the university of California in San Francisco. Ageing with developmental disabilities at the university university of ill, and two centers of independent living at the university of Kansas and university of Buffalo, so there is a lot of activity but where do we go from here? Working together is one way, working with other agencies to deliver program leverage or program resources and amplify the effect that any one agency, or anyone program can have. I think change is the order of the day. I think we are all dedicated to the goals. I think it is a question of how we change because while change is certain, progress is optional. And so we have got to work together. And we have got to focus on what needs to be done, and go do it. And so I'm going to break through, we talked about the same thing, and government can't do everything, even though we represent government agencies, and can be leaders in this effort, we need to work with the private sector, with the nonprofits, and everyone together, so that we can make this substantial progress, and not just talk about community living, but really live community living. So as you hear the other perspectives, and presentations, I hope you will keep that in mind. We are all in this together, and we have got a great track record of getting here, but we have great challenges as we go forward. So let me introduce Roy Grizzard once more, Roy, tell us about employment.

## (Applause.)

W. ROY GRIZZARD: Thank you very much, John. It is a delight to be here. It is a delight to be with this extremely distinguished panel. It looks like a homecoming with some of the folks that are in the room. We all know each other well. I would be remiss if I did not thanks Susan Parker from the office of disability employment policy, and her staff for their tireless efforts in working with the entire committee that put this particular conference together. This is an important conference. This is an important issue, and I think that secretary Hager has certainly started us off in the right direction, and it is kind of like he and I are playing a tag team. This is the second venue that we have been on today as we had a meeting earlier on the emergency preparedness plans for people with disabilities. So it is a delight to be here today.

Material life can be a sign of increased productivity. The sharing of accumulated knowledge with others, and good health if one plans for it properly, and has the right supports. In history, aging and health problems were seen as reasons for terminating an employee. An older worker was often replaced by a younger worker, and even if the older worker needs' could be easily addressed, they were often let go. Disability was seen not as a normal part of the aging process. Rather, it was a circumstance to be dreaded because it could result in financial ruin. I would like for you to reflect back just a moment to the remarks that I still want to say secretary, Allen because I have known him so long, but the remarks Claude Allen made during the lunch hour, that a concomitant of aging is often disability. And I put it in a different way. When I make speeches, I tell folks when you get over 40, your body starts to talk to you.

### (Laughter.)

And so it is important that we address these issues. John is already quite amply talked about President Bush and the New Freedom Initiative. Part of the New Freedom Initiative, of course, is reintegrating people back into their communities with disabilities, or aging population being able to have assistive technologies, and opportunities to work and to fully participate in those communities. And this, the fruition of the NFI, is being created through more accessible systems of cost-effective community-based services. These services ensure that becoming older, or acquiring a disability does not disenfranchise a worker from the American dream. The dream of pros pros per it tie through hard work, the New Freedom Initiative has the following key objectives. Increasing access to assistive and universal design technologies. You have heard about that earlier today. Expanding educational opportunities as John has talked about. Promoting homeownership, and of course integrating Americans with disabilities into the WORKFORCE. Expanded transportation, is also an option that is laid out for the New Freedom Initiative and promoting full access to community life. Well disability, is a common aspect of the normal life process that goes through life. Nothing to be feared. In the 21st century, it doesn't have to negatively effect, or impact the performance of any worker. All the workers -- older workers can thrive in their job and in the changing needs that can be addressed. Let me say that all types of sensory, physical, health related and emotional disabilities can be accommodated in a variety of ways through assistive technology use, through the job restructuring, through ergonomic design, and through job sharing, reassignments, and through flexible scheduling. The office of disability employment policy, ODEP, has taken the lead at the U.S. Department of Labor in accomplishing the working goals of the New Freedom

Initiative – the work related goals of the New Freedom Initiative. ODEP promotes innovative strategies that accommodate the health needs of American – of the American WORKFORCE. ODEP's goal is to ensure maximum productivity and career options for all workers including older workers, and those with special health needs. For example, we provide the job

accommodation network, which is a free service, which provides consultant services to accommodate the disabled and the health problems that can accompany getting older. ODEP is conducting research on the use of customized employment strategies to address the employment needs of individuals with significant disabilities. Customized employment is a blend of services designed to increase employment options for individuals with significanthealth needs. Customized employment is a highly individualized approach to job placement that starts with the needs and the interest of the individual person with a disability.

It creates through negotiations with an employer a new job description unique for that individual. The customized employment placement must match the task that the job seeker wants to perform, and can perform with the business needs of the employer. Customized employment allows an older worker to succeed. The job is at an integrated work site. Examining the prevailing wage rate while accommodating any special needs that that individual has. ODEP works with the employers to educate them about the needs of older workers. This includes advice on how to accommodate their health issues. Let me say that the job accommodations network can be contacted by going to the website of J-A-N.WVU.EDU, and we suggest that those that are concerned with having older workers to be able to continue in the workplace with some accommodations that this is an excellent tool to be used. The problem of growth in the labor force, will be affected and by the aging of the baby boomers. That generation. In other words, persons born between 1946, and 1964. In 2012, baby boomers will be 48 years of age, to 6 six years old, the number of workers in this age group is expected to increase significantly over the 2002, to 2012 decade. The labor force will continue to age with the numbers of workers in the 55 and older group projected to grow by 49.3 percent. Four times the 12 percent growth projected for the overall labor force. The numbers of 35 to 4 four-year olds is expected to shrink as the baby boomers shift to older groups. Increased longevity is also redesigning what it means to retire. An increasing number of workers will be retiring over the next two decades. The sheer numbers of older workers means that many employers will be coping with aging -- with an aging WORKFORCE. The numbers of people in the labor force age 65 and older, is expected to increase more than 3 times as fast as the total labor force due, in part, to the workers postponing retirement. Compared with the total labor force, the numbers of workers younger than age 45, is expected to grow more slowly, or to even perhaps decline.

For example, the AARP reports that nearly 70 percent of may tour workers intend to work beyond the traditional retirement age. Many of these workers, will experience disabling conditions placing an increased pressure on the employer to have employees who are temporarily disabled return to work quickly to maintain productivity, and services. This issue present ODEP with the challenge of suggesting and influencing policies and practices that empower employers in rethinking their strategy. And these strategies include employee recruitment, development, and transitions with the goal of retaining long-term high quality, high contributing employees. I think that those of you who know me, know that I speak best often from the heart. So I have had enough talking for today. Let me put it this way: It is important for us to retain what we call the institutional knowledge also in those workplaces. Those individuals that might know that brick is filed under C insteaf of under B because it is made out of concrete. Those people who know how to get things done. They will be invaluable to the American WORKFORCE. I have given you the prepared statistics now. Those are good numbers. Basically what it is saying is that there would be many opportunities for aging Americans to continue to participate in the workplace, and to employers who those dedicated and hard working individuals, who like myself, are grained, that those individuals can be great contributors to the workplace, and that they can meet the health and aging related disabilities that those folks bring to the workplace. At the Department of Labor, the office of disability employment policy will will be working to provide opportunities for those employers, to learn how to accommodate individuals request disabilities who are in that aging workforce. They will be there to provide services such as the job accommodations network that will provide that expertise on accommodations.

I believe that as we move into the ensuing decades that technology will continue to change the playing field on which we all work, and through universal design, and additions to the technologies that will be developed over the decades, that it will enable individuals with disabilities, older Americans with disabilities to continue to provide good, solid work in the workplace, to contribute to the goals and the missions of the organization for which they work. And I believe that it will allow them to have a continued vitalized life, and that they will be able to participate in the total discourse of the community, and that they will be a valued citizen, and that it will enhance their years of age, and they will be able to continue to live independently, to provide for themselves, and their loved ones, to lessen the burdens of social services that need to be given, to continue to be an inspiration to the younger generations that come along, hard work, good work, professional work, is worthy. It dignifies our life, so at the office of disability employment policy and the Department of Labor, we will continue our commitment to provide opportunities for work, for people with disabilities of all ages, and particularly, as we look at the numbers that I just alluded to, we will continue to reach out and to provide those opportunities to the aging workers in America, so that we will all feel that we are a vital part of the American community. Thank you.

JOHN HAGER: Thank you, we all know how important employment is and you are a greet leader in this arena. DR. AGARWAL is going to share in a PowerPoint with us, and we appreciate her being here representing Dr. Mansfield.

MADHULIKA AGARWAL: Good afternoon. Thank you, Mr. Hager for a very kind introduction, deputy secretary Mansfield sends his regrets for not being able to be here today. He had budget issues have overtaken his schedule. Thank you also for the opportunity to talk about some of the ways we are supporting the president's goals for the New Freedom Initiative and -- three weeks ago, the national Veterans -- were held in Minneapolis, where 500 wheelchair athletes competed in a variety of sports events, like softball, basketball, the wheelchair games are one of the four events that the department sponsors for veterans that promote an active life-style and engage aging -- and take advantage of the therapeutic aspects inherent in each activity, the wheelchair games afford disabled Veteranses to push themselves to new his, to realize their full potential. Young veterans who

have just returned from Iraq, and Afghanistan with new injuries had a chance to see what other Veteranss with similar injuries have accomplished. Programs support the assistive living needs of our aging veterans, and our new generation of veterans. The specially adaptive grants provides grants for Veteranses with disabilities requiring the use of wheelchair, or for Veteranss with loss of sight. During the past year, the vocational rehabilitation and employment service has implemented initiatives that provide Veteranss with the true access to accessible technology, assistive devices, and home modifications.

Accessible technology includes voice recognition software, magnification software, communication devices, and alternate key boards, assistive devices include amplified telephones, accessible work stations, medication reminders, dressing AIDS, ERGONOMIC products, and alarm systems, it includes adaptive housing modifications such as ramps, accessible home interiors, bathrooms and kitchens, and stairways, we as case manager will provide independent living services to the Veteranss with severe disabilities receive the available technology, assessing the needs with person of persons -- and accessible technology in our rehabilitation programs. Another important area in which we are responding to the president's goals for the New Freedom Initiative, is in telehealth, including telerehabilitation, and web based delivery of health information. Particular emphasis has been to use home telehealth to help veterans remain in their own communities and live independently when appropriate instead of going into long-term institutional care. This is right care at the right time in the right place.

Technology utilizes information, and telecommunication to deliver care where the patient and health care providers are separated by distance and/or time. We are currently developing the use of telerehabilitation to make specialty care available in local VA medical centers and community based output patient clinics, telerehab is being implemented -- the -- with diseases like MS, or spinal cord injury, or amputations following disease and orthopedic disorders to interact with their clinicianness real time using video conferencing. This avoids unnecessary travel. The second model of telerehabilitation is ongoing assessment and care, which enable it is VA to deliver care such as speech therapy, or physical therapy for those who are at distant clinics from a medical center, a third model of rehabilitation is consultative care by let's health care professionals to coordinate care in an interdisciplinary fashion, a fourth model is providing telerehabilitation directly into the home. Given a choice, most of us would prefer to receive the care in our own homes.

One of our most innovative services, and is being served as a web portal that provides one-stop shopping for the VA benefits. In 2003, we launched our first program, which featured the health education information, some self-assessment tools, some very much -- for specific conditions, seasonal health reminder a wellness calendar, and also other benefits. As of 2004, we have begun to provide some more services including personal health information, as well as some commercial health education library that offers updated information about medication and conditions, a prescription checker. Veterans can also build an on line personal health record by entering their health information into a secure storage where this can be downloaded into an ID card.

For those who prefer to remain at home despite their complex disabling conditions, the va has demonstrated that we can help them remain their, maximize their independence, and reduce nursing home days, this patient focused approach supports the wishes of most patients to live at home in their own communities for as long as possible. In fiscal year2004, half of the va's total extended care patient population received care at a noninstitutional setting. Or community based setting such as home based primary care, contract home health care, adult health care, and a number of other programs.

Our home-based care program is a unique model for delivering honk-term comprehensive primary care in the home environment with complex chronic disabling conditions. It also provides treatment by interdisciplinary team. Office of research and development has a long record of contributions related to assistive and university designed technologies. Investigators at VA center of excellence on wheelchair and related technology currently evaluate commercially available designs and develop and concepts that improve mobility with those with paralysis. They investigate ways on the use of the chairs, and develop enhancements for special populations such as those with spasticity. The department also sponsors centers of excellence that conduct ongoing research assistive devices relating to hearing loss, a new center of excellence for advanced technology will now focus on how to use new technology that interfaces seemlessly with the human body. I would like to briefly touch on two topics related to employment of Veteranses with disabilities. The work program is an important part of the president's initiative to ensure that adults with serious mental illness can live and work in their own communities, this goal has added significance, many of whom have the added burden of combat injuries, or combat related traumatic stress. VA compensated work therapy program offers therapeutic sell shelter and workshops at a wide range of vocational lie oriented services for Veterans, the program enables them to negotiate the demands of the real work environment and assist with the integration back into community employment.

The IT program, was was recently signed by secretary Nicholson. It is an understanding with the va's office of information and technology -- the IT program, introduces young veterans who are severely injured in battle, to possible employment within the VA. These returning veterans get valuable work experience as volunteers. As of June, 35 disabled service members had joined the red IT as interns, we hired 15 of those vets when they were discharged in the military and the remaining 20 interns returned home with new skills, they share an eagerness to restart their lives a willingness -- it is imperative that we find meaningful work and establish themselves in the community. Again, on behalf of the department, I want to thank you for the opportunity to talk about some of the ways we are supporting the goals of the New Freedom Initiative at the VA. We have the privilege to make good on the promise of the grateful nation to offer healing and compassion and hope. We are the guarantors of president Lincoln's promise, past, present, and future. To care for those who shall have borne the battle and the widow and the orphan, there are 230,000 men and women who stand ready at VA facilities nationwide to help aging Veterans have productive lives in their community, in closing, I ask that your thoughts and prayers be with our troops, the men and women fighting around the globe, my God bless our troops and God bless America.

JOHN HAGER: Thank you so much for sharing activity at the Veterans Administration, we now have two responders, John Lancaster and Ginny thornburg, and Ginny, I think you are next in line, so – actually John is next.

JOHN LANCASTER: I will stay put if that is okay with everyone and, you know, Gene Sperling talking at the pod diem, you wouldn't see the top of my bald head. Good afternoon, and thank you for this opportunity, Jennifer and others who invited me to be involved in this panel to respond to the distinguished panelists, assistant secretary Hager, and assistant secretary Grizzard, and dR. AGARWAL. It is a pleasure to do so. I want to quickly make a couple of remarks about my organization, the national council on independent living. And react not only to the panelists, but also to some of the things that we have been hearing all day. To start with, the national council on independent living is indeed, as Mr. Hager said, the oldest cross disability organization, grass roots organization in the country. We have been around for quite some time now. We are in essence, a disability association. We are made up of centers for independent living around the country. Due to the great programs that have been developed in Congress, and they are now administered through the rehabilitation services administration, there are approximately 394 centers for independent living in this country that are receiving federal financial assistance. And indeed, there is at least one of those federally funded CILS operating in every congressional district in this country but five. So the country is fairly well covered. You have got a few more to go, but they are getting there, and more are popping up every year, and eventually the whole country will be covered.

Most of those centers, approximately 70 percent, 68 percent, are members of NIKL. Initially, almost all of the state independent living councils are members of NICL. And we do a variety of things, we provide membership services to those centers, we have group insurance policies that they can buy into for their centers for theirofficers and directors, for their employees in terms of long-term disability, in terms of life insurance. We do an annual conference for them every year. Most importantly, we do extensive training programs, which again, are supported in part through the rehabilitation services administration with their funding to the independent living resource utilization unit down at Texas institute of rehabilitation and research, and we in partnership with IORU run what we call IOLMAN and I know some of you have participated in those trainings. And those trainings cover a variety of things improving center operations, current issues like issues related to long-term care. Deinstitutionalization, Medicaid, and Medicaid reform, Medicare some of the issues that we are now facing with the Medicare modernization act, these are the sorts of things that are addressed through the IO net training, but the main service that we providef or our members is to be the voice in Washington, D.C.. we represent them up on Capitol Hill before the administration, we are in there fighting to maintain appropriate funding for centers for independent living around the country, and I must say we appreciate the support we are currently getting from OSERS, and RSA and the good working relationship that we have developed with RSA, and NIDRR in terms of getting a good dialogue and cooperative working relationship between the CILS and the funding agency, what do the centers do?

Basically they keep people productive. All of the things that we were hearing this morning about staying in the workforce, about setting up the health care and the other streams that dah, dah, dah, dah, dah, we have been talking about these things for 30 years. Finally the folks in the agency community are starting to get it. I think the lit bulb is starting to go on. That is all right. All right. You know. This is good news, somebody is listening. So we, none of this is new to us. And centers are seeing an increasing number of aging people coming to them. Folks like myself. And us old gray hairs, these fat bald guyness wheelchairs who want workforce. There are centers are seeing more and more people with disabilities. We know from a variety of surveys that many organizations have done that elderly people don't want to be going to nursing homes. It is usually happening because of Federal Government funding streams and state government funding streams. Often Medicaid and also Medicare. Tremendous institutional bias. I think it is just disgusting and shameful that in this country in the year 2005, 23 states still spend in excess of 80 percent of their Medicaid dollars on institutional care. We ought to be ashamed about that.

# (Applause.)

JOHN LANCASTER: And based on what we know, there is no reason for it anymore. Absolutely none. In the State of Tennessee right now, members of adapt and centers for independent living are occupying the state house and occupying governor BRETTESON's offices, and do you know why? Because of the draconian changes he is making in Medicaid are so bad that they are actually going to start denying service to people who are on ventilators, people who have other acute health care needs, many of these people are living independently in the community, and without that support, not only will they be forced into institutional care, they may end up dead. And he has said to them right to their faces, tough isn't it? That is the way it is.

This is what we are up against. And it is pause for thought, especially if you are 65, and want to keep going out there in life and, you know, the old things are starting to creep in. There was a comment that somebody made earlier, about Dr. Grizzard I think it was, that your body starts letting you know you are over 40. Well, it does. That doesn't mean life is over. Disability is as he said -- so there is lots of issues that we need to be addressing not the least of which when you are talking about productivity, is the whole process of how do we delink these issues of long-term care supports of healthcare from employability. They are not the same issue. One ought not be contingent on the other. You should not have to be declared unable to work to be able to get the types of support you need to be productive. I mean, that is just lining catch 22 bizarre reasoning. But that is the way we basically set it up in this country. We need to relook at social insurance in this country, and I say we need to create a system -- and there are others working on thius. We had an Illinois summit here about a week ago, Brian McDonald and Glen white organized it and others, and we talked about this issue. And we need to resurface the idea of a universal social insurance program that will deal with these issues of disability and long-term care supports that is payroll based. That is based and is a WORKFORCE incentive program, an incentive program, an insurance program to keep people productive. Not to get them out

making the incentive to get out of productivity. We have got to shift the whole way we have set things up here. And we are --some good things are starting to happen. We hear some good things coming out of CMS and a few other places, but basically, it is slow. And I have some questions, actually, for our panelists. I will be more of a Respondent now, if I will.

And one of them in particular, I have for Dr. Grizzard, and that is several years ago, the ticket to work, workforce incentives improvement act, was rolled out, and I think I got it all right, -- and these particular etc. Became available, and supposedly all of the incentives are in place now for people to start jumping off the disability rolls, and going to work, and being able to retain their health care supports or whatever else it is that they need, but yet, only a couple of thousand, a little over 2,000 people I think in the entire country have taken advantage of this program. Why is that? I know the program is administered out of the Social Security Administration, but the office of disability employment policy I'm sure you are thinking and talking about this, and I would be interested in hearing from Dr. GRIZZARD what it is that you are intending to do about this, and how is it that you are working with the Social Security Administration, so we start seriously putting a dent in this and making these incentives work if they are workable, and if not, let's make them workable.

W. ROY GRIZZARD: What and on the spot question. I suppose that I could say where is Martin GARY, or BERTE, APONTE, who is handing out, I believe, -- heading up a commission now that is taking a look at the ticket to work. John, as you well know, that particular piece of legislation and the administration of it is in the purview of the Social Security Administration. And prudence would be for the expertise to answer to that to come from them. However at risk, I would say that with any new program, one of the things that I -- and this is personal opinion, and not official, is in the manner in which it was initially marketed. I think the ticket to work came in it was right there with the value pack and the pizza thing that went in the trash can with a lot of phonings. I also think that the support was not there in terms of providing the assurances of waivers or whatever we needed, wrap arounds to provide the assurances of health -- of healthcare, and then I suppose one of the issues that is probably being looked at was in terms of the various networks, because from what I understand from afar, is that in various states that primarily, VR remained the only major network, and I think that had something to do, probably, with the manner in which the milestones were to be rewarded to whoever was doing the network, or was doing the training.

I think that like often many new programs, here is an important thing I think sometimes you know, we get into this velocity of ready, aim, fire. And we spend so long aiming that we never fire. Maybe that was an attempt to say ready, fire, and now it is being refined. I think that that would be more appropriate though, for Social Security to respond to, or those that are working on this commission with the ticket to work. And so I think that unless my colleagues have a more definitive response, that the best thing for me to say is that from my perspective in looking at it from what I do, that it is a work in progress, and that I hope that improvements will come to it so that ultimately more individuals will take the opportunity to redeem the ticket and begin a training process that will ultimately lead to --..

JOHN LANCASTER: For dR. AGARWAL, recently the high level pan advisory commission, if you will, that was appointed about eye the previous secretary, was to evaluate the Veterans Administration rehabilitation programs for disabled Veterans, particularly those that were returning fromthe Iraq war, but all disabled Veterans in general, who had the emphasis on outcomes, and employment outcomes, and independent living outcomes. One of the big harps and criticisms that came through loud and clear in thatreport, and that panel by the way was headed by Dorcas Hardy, who was --Kicked this thing off here this morning. But one of the recommendations and criticisms, and recommendations that came through loud and clear in that report, was that the VA was falling far short in terms of providing veterans with very severe disabilities, in particular, traumatic brain injuries, spinal cord injury, and other serious disabilities with appropriate independent living skills training so that they could live independently in the community, and make sure that they had brokered all of the supports that they needed so that they in turn, could be taking advantage of the vocational rehabilitation programs offered by the VA. And I would like to know, what if anything the VA has done to implement the recommendations in that report, and innic particular, in the areas related to independent living?

MADHULIKA AGARWAL: One of the advantages of being on this panel and a member from the department, is that I have not seen the entire full recommendations however what I can tell you, is that for returning veterans especially those that have had complex injury, we have four programs, very comprehensive programs that have been set up at four different sites in Minneapolis, Andy ago, Richmond and Palo Alto, that are taking care of the picture for returning vets. And at this time, it is to have at least one site in every network, which would have very comprehensive set of abilities, from clinical care of course and research and also be doing some outreach and the care coordination that is required for these individuals to be established back into the community. There is a full program that is being developed at this time for the entire spectrum of the care, the focus on returning Veterans, level 1 being the most comprehensive, and the tertiary care centers which have all of the care that I described, to a level 3 -- the level 4 which is the least, there would be points of contact that would then coordinate with the levels 2, 3, and 4 that would be available across the entire system.

JOHN LANCASTER: The other thing that I would like to have all panelists I think address and finally and then I will turn it over to my colleague, Ginny thornburg, but I would like to hear and get a sense of what it is that the agencies are doing collaboratively and how it is that you are working together to fully implement the and put into action the president's New Freedom Initiative.

JOHN HAGER: Well, I will do -- quickly, John, thank you for the question. We at OSERS have three agencies that is NIDRR and the office of special education OSEP, and the rehabilitation services administration. And in many of our new priorities of the

programs, we are becoming collaborative. And let's say the example of the transition program, trying to take youth who are working their way out of special education, and may not have anywhere to go in life unless we can help bridge that gap to secondary postsecondary education or the workplace, and so we are very focused on transition programs. And in that RSA and OSEP and NIDRR all through a part of the new priority, the new initiative which is unprecedented for OSERS that we work together on the same program. Meanwhile, we are trying, we met yesterday with Dr. Giannini and Michael MARS at HHS focused on a program for deaf and hard of hearing employment. So that is a perfect example of where we are trying to of a strong part of their originally initiative on serving the hearing community. Those are just examples. I mean, we with Roy last weaning in Philadelphia, at a town hall meeting, at their conference. So my examples go on and on. We are trying very hard to do just what you just said.

>> Thank you, John, I feel a lot more expertise in speaking to that one than the last one which was more of a Social Security question. But at any rate, to carry on as John was saying, I think that there is a lot of SYNERGISM that is going on among the various agenciness the Federal Government. Just today, John as already alluded to this, we had a meeting over at the FCC where we were rolling out the emergency preparedness – a report to the president that is going to the president, and then the accompanying committee reports on what we are doing together, to help people with disabilities to be prepared in times of emergency whether it is a man-made type of emergency, or one that comes from,

for instance, weather events. That is important in terms of employment. It is important in terms of people who are elderly or senior citizens. Because we know that to have people in the workplace with disabilities, they need to work in a place where they feel comfortable, where they feel like they are not and after thought if there is an emergency, but that preparations are made in advance. And so if you want to go to the websites of almost, let's say, John, I think it was 20 agencies involved in this particular report, the department of homeland security is releasing it. You can look for the work related preparation, for buildings at the ODEP website at DOL.GOV, front/ODEP. This is an example of 20 federal agencies coming together to make the workplace safer for people with disabilities, and for senior citizens.

We have an ongoing collaboration with the Department of Transportation as lead, and we have projects that have been developed such as you nighted we ride that involves participation of the Department of Education, HHS, Department of Labor, and the Department of Justice and EEOC. As many individuals in this room know one of the greatest barriers to employment for people with disability, and also the great barrier to the economically disadvantaged, or to the elderly, is transportation. And so we have sometimes funding sources that basically allow moneys that go down to the local communities that can only be used for, for instance, VR services, or for services for senior citizens, or for services to economically disadvantaged. And so the idea came up is that if a vehicle that provides services, for instance, for somebody with a disability and they are taking them to a job training site that is going down Constitution Avenue over here, and there is somebody else that is there that needs to go to a senior citizen -- a senior center, or maybe dialysis or they need something that is related to age, and they can't drive because they are elderly. They have macular degeneration or hip replacement, what ever, that that same vehicle could pick them up. Or if it is a disadvantaged person that is a welfare work program and they have not obtained enough to get a vehicle to get to the workplace and it is all going the same direction, we work together and we work together on a day-to-day basis at the Federal Government on these various issues. We are doing it on mental health, substance abuse issues, homelessness, and I could go on and on on those things that we are working together for.

JOHN HAGER: I thank you Roy for the great answer, I think our time is getting shorter, and shorter, because of our slow start. And John, thank you for your good questions, and for your good participation.

### (Applause.)

We have got one more wonderful speaker, and she has been very patient and I feel bad leaving Ginny thornburg for the last but I know she can handle it. So Ginny.

GINNY THORNBURGH: I am a until nervous about a topic called promoting community living because there are some aspects of community living that have not been talked about, and you and I were raised politely to not talk about them. And everybody in the room knows you don't talk about politics, and you don't talk about sex, and you don't talk about religion. Those are the 3 topics that you know, you just kind of hold off. And I am going to talk about religion now. It has not been mentioned so far today. Those of us who are older, those of us who have disabilities have a right to be welcomed in the house of God of our choice. The congregation of our choice whether it is a parish or a temple or a synagogue, or a church, or quaker meeting house, we have a right to be welcomed, and accommodated in that house. This is not imposing religion on people. This is totally a matter of choice, but if we choose to go there, those of us with disabilities have a right to be accommodated no matter what our disability is. And our community represented so absolutely by these speakers have put no muscle behind spiritual and religious access, we put lots of muscle behind education and employment obviously today, transportation has been mentioned, health care has been mentioned today. No one so far has spoken of our right, our right to bewelcomed and valued and affirmed in the congregation of our choice, and statistically, with he no he that as we age, our faith becomes more important to us. The people who have contributed their time, their money, their attendance in congregations since they were young, as they age, are they honored? Is adequate lighting, is large -- are large print bulletins, are decent sound systems? Assistive listening devices, are designated parking last places, PEW cuts, and more than all of that, is there a genuine time of dignity and respect for those of of us who may have some disabilities, but we have got a whole lot of ability. And I know it is not popular, I can see it on your face. You are not supposed to talk at a government meeting about religion, but guess what our leader has so spoken. I hold in front of

me the New Freedom Initiative, which our panel is charged with reacting to. What are the next steps to implement this document that our president issued February of 2001. And you probably didn't get to page -- the second to last page, page 23, I was reading the thing, reading the thing looking for access to faith, access to the house of God of your choice, and sure enough, page 23, promoting full access to community life, which is what we are charged with talking about, and it says, "Americans with disabilities should be fully integrated into their communities, and civic and religious organizations are vital parts of those communities. Too many private clubs, churches synagogues and MOSQUES are inaccessible and unwelcome to people with disabilities, as a result peoplewith disabilities are often unable to participate as fully in community or religious events.

And you know what happens to us when we get older? We have been to bedrock of our congregation, and we start noticing we are not hearing as well, we are not maybe seeing as well. We have some new imbalance, and people rush around kind of fast with us, and we are a little nervous about driving or maybe walking when the leaves are wet, with he have to parkway over there, we have to walk the leaves are wet and we are a little nervous about slipping so then we stop not coming as much, when being in community is even more important to us than it was when we were young. We stop -- we start not attending. And then, we don't attend 3 Friday nights to the synagogue, 3 Sunday mornings at the parish, and no one is called, so we think gosh, well, I saw on TV. Maybe I don't need to go. When the congregation being in community means the most, we are not there. And often, religious leaders come to visit us once a month, the RABBI will come once a most the priest will come and say prayers and do stuff in our house but is it not the same as being in the congregation, and you and I have to add to our agendas the fact that congregational life is an integral part of many, many people's lives. I remember my mom as she no longer was able to do the many things that she was able to do when she was younger. She was 90, and I said to her, mom, which of the disabilities that you have now, which one is the toughest disability for you? And at 90, she had a wholeseries of disabilities, and she took a moment, because she knew about my work, she knew about how much I cared, how much our family cares, how much you care, and she said this answer, and I lay this one on your heart. She said at age 90, no longer feeling useful.

That was the toughest, not incontinence, not being blind or deaf or walking, no longer feeling useful, and we today hear as we propose the resolutions to go to the White House conference that will meet in this great year, 2005, if we don't say something about what our congregations can and must do if that is not part of one of our resolutions a part of community life, we have missed out. Our organization as many of you know, promotes the full access and full inclusion of 54 million Americans in the congregations of the nation. And if you want to talk about it with me, I'm available. Thank you.

## (Applause.)

JOHN HAGER: I would like to thank you all our panelists. We have had a fascinating session, we have run out of time but to sum it up very quickly, I think there are two things that I take away. Number 1 is that we do work together, with he have different perspectives and we have different programs, but we work together to improve our efficiency and our effectiveness, and finally, it is all about freedom, employment to enabletechnology to assist it, independent LIVING TO allow it, religion to enhance it and government programs to support it. So let's go forward, thanks.

### (Applause.)

MARGARET CAMPBELL: Let's bring everybody back together again here. For the last panel of the afternoon, this is the panel on research, solutions from research and development. As everyone is taking their seats and getting into their applieses here so we can begin in a few minutes. Recognizing the obvious here, that we are running right now, we are running considerably behind. What is it 45 minutes behind? Is that about it? . I think thefact that we are running behind speaks to the fullness of the agenda, and the richness of the agenda. Whenever you bring two networks together, aging and disability it sort of expands the space. So that is what we are faced with now. My name is Margaret Campbell. I'm on the staff of NIDRR, and I also have the honor of being the co-chair of this event with Winthrop Cashdollar. If there is anyone in the room on the planning committee, stand up. Please stand up. As Susan Parker said she is not in the room she is on the planning committee also, she said it was the best planning committee she had ever been on, we ended up liking each other at the end, which I think is wonderful and remarkable. My role right here is to introduce the moderator of the next panel, and I do that it is really a pleasure and honor to introduce GIL Devey sitting over on the right, earlier somebody talked about pioneerness the field, well when you meet Mr. GIL Devey, pioneer in rehabilitation engineering research and administration, I would also say that GIL is a personal role model of mine in terms of demonstrating productive professional aging, as well as overall aging. GIL will serve as the moderator this afternoon, as well as offer remarks ice his on, let me say a few words about what is he it is in your packet in the biosketch so I will be very brief for the sake of time, but GIL served since 1993, as the program director for by on medical engineering and research to persons with disabilities at the National Science Foundation, as I said this is a position that he has had since #13E9 but he has been with NSF since 1964, and over the course of his 40 years, he has had a very distinguished career, he has been a strategic planner in this area, planning research, a promoter of the research, a mentor for many young vest GAtor, a sounding board for young investigators and their ideas, he has really played a key leadership role in the entire field and he has received numerous honors for his contributions to biomedical engineering, and specifically medical inSTRU PTtation, so please join me in welcoming GIL Devey will serve as the moderator for this session.

(Applause.)

GILBERT DEVEY: Thank you very, very much. Margaret, and now I realize I'm my own role model.

(Laughter.)

GILBERT DEVEY: Anyway, we will see how it goes. Thank you for original analyzing this session, and especially thank you for having me serve in this role. We have spoken a lot about many various policy laws, programs, desires, and so on so far. We haven't yet spoken about the basic science, the life sciences, the research and development programs, large large in number supported by the U.S. Government that are -- have many aspects of them directed to this field.

So I thought I would show several federal agency initiatives that bear heavily on your aspirations for helping the aging and disabled. The NIH road map, for example, is only a couple of years old, which is searching for new pathways to discovery. research teams of the future, who focus on multidisciplinary, or interdisciplinary activities, and then very interesting, the reengineering the clinical research enterprise, one of the few times NIH has been known to use the word engineering. I say that because I am one. Then also, the FDA recently, a couple of years ago, adopted a challenge and opportunity on the critical path to new medical products. FDA has been considered a bottleneck from time to time in the making available new medical technologies. This is a a report, you see the URLs for both of these reports on the bottom of the slides here. Then in January of 2005, the Department of Health and Human Services, issued a report called moving medical innovations forward. New initiatives from HHS. All HHS agencies were involved either formerly or new it was happening, certainly, and we see here the memoranda of understanding, that were executed with nonHHS agencies who through significant support for research in medical healthcare activities. Amongst them are the National Science Foundation, the national institute on disability and rehabilitation research, the telemedicine and advanced technology research center of the Army, and other nonHHS, HH agencies. You can see the other four action items that are also on that list. Just yesterday, July 20th, the national Academy of engineering and the institute of medicine released the report engineering health care partnership with the goal to transform the US healthcare system from an underperforming conglomerate of independent entities. Margaret mentioned something about the 60s when I was involved in some of this, and the then much younger senator Kennedy described the US healthcare system as a cottage industry. Now it is just an under performing conglomerate industry. So I guess that much has changed. That is a very important concept, actually. Anyhow, it is going to be changed into a high performance system in which every participating unit recognizes it's dependence and independence on every other user. So the Academy says. Last week, my presentation here, we have heard several presentations today concerning the matter of what happens when you age. And here is a slide measuring and monitoring success in morbidity. The first time that was used today, which is different of course now from the other words that were used to describe aging, disability. Notice the top line here shows by the way, this was done in 2003. Either we have made great advances since that time or it was a scenario that was going on here. But as you see here, present morbidity and over here at the age of 55, the morbidity starts to increase, and that person dies at the age of 76. I think even the year 2003, the 65 should have been in there instead of 55, and maybe even 80 at the 76 level. Anyhow, let's look at the very bottom line there, where it shows morbidity starting at age 65, and still they are having us die at 78. Well, I have done a lot better than that so far myself, so --

### (Laughter.).

I always know I was abnormal, I didn't realize how. In any event, this is another example of what I have been speaking about previously in different talks. With that, let me stop and introduce our first presenter on the topic of healthy long-term living by Stephen Bartels, who is the -- a professor of psychiatry at dart mouth medical school, director of aging services research at new hamsure dart mouth psychiatric research center. Stephen.

STEPHEN BARTELS: Thank you. It is really a delight to be here, and I am given the task of talking about healthy long-term living which of course is a huge topic and I'm going to need to move quickly since we are running real late. But what I hope to do is very quickly say something about what is healthy long-term living. Just so some a few examples from research of some things that we learned about longitudinal predictors and some strategies regarding prevention, intervention, something about threats and challenges, and then we have all been challenged to say something about to suggest an agenda, a research agenda, so I have taken that on, and we will present that also in terms of my personal thoughts. So what is health I didn't long-term living and what are the operational concepts? ROWAN, KAHN --, there has been many definitions over the years, this is a very good one. And then consumers or older person versus also been asked in the recent paper that got published, 4,500 people asking them what they thought about what was successful aging. You can see listed here a host of things but these all make sense having to do with remaining in good health and being socially involved and being engage in meaningful activities having control over your personal decisions adjust to go aging well, and being free of disability as much as possible and acting according to your standard values. And these all make sense and we wouldn't expect otherwise but certainly they focus on physical, psychological health as a component, as we thought about this over the years the issue of aging longer but also aging better, is paramount and it is not about quantity but quality of life ultimately that is really important and that includes maintaining both mental and physical functionings with normal changes of aging we are adding life to years, not just more years to life. So what do we know from research and healthy long-term living there is a huge amount published I'm going to touch on a couple of points just to make some examples.

There are a number of long-term studies that I'm sure many of you have looked at. There is two here that just mentioned by way of example, that the NUN study looking at protect assistive packtors against developing Alzheimer's Disease and the Harvard study, by George valiant the real take homes from the longitudinal studies, is that the long-term predictors of aging are largely associated with things that could be modify able, there is certainly genetic variables we all know about but more than we imagine have to do with life-style, healthy behaviors, psychological and social behaviors, the extent to which we engage in physical activity and which we engage in mental activity not using alcohol or drugs, to be socially engaged religiously engaged as we just

heard, minimizing stress and addressing mental disorders early are all things that if worn out over time have been predictors of healthy aging.

And there are things that we can do of which the literature in gerontology, there is a host of things that we can do that are important, for example, musculoskeletal and cardio respiratory systems with ages exercise at any age is important, and it had significant effects on not only muscle and skeletal systems but as we know reduces osteoporosis, aerobic exercise, lumbar spine exercises all have an impact on minimizing the effects of osteoporosis, and most importantly reducing risk of fractures with false which put people in nursing homes and lead ultimately to not only morbidity but mortality, activity is good for cognition use it or lose it and participating in cognitive activities possibly can reduce the likelihood of eventually getting Alzheimer's Disease or at least minimizing early on some of the effects of early cognitive impairment by building up cognitive reserve, and leisure activities and even exercise can enhance cognitive functions so everything that we have heard that we should do investerdaying exercise eat well and exercise your brain are true. And make a lot of sense and it is not too late to start at any age and make a difference. And then there are examples of preventive early interventions that we know including other areas for life-style depression intervention a number of studies that have looked at looking at individuals who have recently had a myocarrial infarction or other medical problem which makes them as risk for depression which makes as difference, there is currently a very interesting study going on on preventing depression in individuals who are older with macular degeneration and treating them for depression. Things of quality of life, also addressing the problem of drinking, there are very brief, 2 to 3 session interventions that a primary care physician can do in an office that make a big difference in helping a person who may be drinking more than 2 drinks as day who places them at risk in older age maybe not younger but certainly when they are older for downstream problems and those have been very effective and certainly very cost-effective. There are a number of studies on large literature now on care giving for persons with dementia who are disabled by Alzheimer's and other disorders and looking specifically at what we can do for the care provider the family member, and very inexpensive interventions including providing a group problem solving and strategies around taking care of behavioral problems. Cheap as dirt but not reimbursed directly often through Medicare or other sources, can decrease or delay nursing home placement for people with serious cognitive impairments by 329 days or more. But also important, that the individuals or the care providers who are part of the interventions have less depression have better stress management and have less medical morbidity themselves including problems with blood pressure, and other medically stress related disorders, so a host of list Ray your here on things that can make a difference, and I think the important message here is that the field of gear ontology, and geriatrics, and thinking about not only treating illness but in fact wellness, and enhancing health, is booming, and the data is really quite interesting, and fascinating in terms of what we are seeing about things that people can do at all ages to make a difference.

So what are the threats and challenges that are really significantly important? Health behaviors are difficult to change, and all of us around the room struggle with these things whether it is sedentary life-style, a diet alcohol, drug, or medication misuse. These are all things that are targets for influencing, and affecting healthy aging. Age relate disorders. There is an epidemic of Alzheimer's Disease, 40 percent or more, approximately 40 percent of people over age 85 have early cognitive impairment or early Alzheimer's and as we age the brain doesn't do as well as the body. This is a huge problem as we know is affecting healthcare systems, Medicaid, Medicare and the like. We need to be able to confront this challenge with effective interventions, and also preventive interventions. Inadequate report healthcare, and the quality -- the institute of medicine has taught us that we are not getting in fact science based treatment and what you get from your normal provider is not necessarily what science tells us to do, a huge challenge, and then particularly for older individuals, multiple medical problems, poly pharmacy, high risk of drug events for the average person who is having 6 or more medications many of which may direct huge problems and also medical errors, unnecessary institutionally based care we have heard about, certainly people with disabilities, we did a study that found about 40 percent of people with psychiatric in nursing home or older were by the consumers and providers more appropriate in the community setting. And then there are health dissparery ties and fragmented services are huge challenges.

I'm going the give an example of one particular area which is people with serious mental illness have poor quality of care and are at risk to die earlier because of health care dissparery ties and behaviors, the health care is poor, and if you look at the healthcare that they get sometimes that accounts for the increased mortality. And the rates of medical diseases are much higher in people with serious mental illness as they age. So what are some of the things that one can think about in terms of practical example, and these are studies that we are involved in but many others are involved in around the country, which are thinking about ways inform think about rehabilitation, to think about skills, acquisition as well as integrating healthcare at the end receiver through care managers, and health education and illness management skills can make a huge difference even for the person who is 70 and has a major mental disorder or other disability, we are also involved -- people with various disabilities engaged in physical exercise and diet programs with health mentors where we give them memberships to health clubs, and help them to think about ways to deal with the huge epidemic of obesity and metabolic disease that they have, so there is practical things that are exciting at this time to confront some of these problems.

So quickly moving to research agenda, I'm going to focus on 4 particular areas that I'm going to suggest for discussion later on today. One, which I think is very, very important, and I know is one that bridges on policy and not necessarily on research, but there is concern within the scientific community that federally funded research is in some peril right now, which is to say that after the crumbling the NIH budget over the last decade there is no longer that doubling, and the funding currently is not keeping pace with even with inflation in this last year for the first time in 24 years. Those of us who have grants used to be looking at funding the best 18 percent or grants that are in the 18 percentile or lower. We are not funding at the 8th percentile so you have to have an A plus to get any grants funded at this point, and then this grant gets cut by 20 percent so my first message is if we are

going to take seriously the idea that aging and research need to be wedded to make an impact on health and healthcare, and to think about the downstream impact on decreasing institutionalization and functioning, we do need to make some difficult decisions around how we can enhance funding for research, and perhaps think about rejuvinating federally funded research and maybe private partnerships and thinking specifically about cross initiatives on research without those tools we can't do the work so the major and most important recommendation here is a policy one.

After that, we know a lot. The research is quite good. One of the problems is with dissemination and implementation of research in the community, and we need good technologies and the VA is way out ahead of much of the health care system the United States on thinking about ways to have evidence based practices, to engage in care management, patient portals we heard about, how do we activate consumers and engage in clinical shared decision-making where consumers and providers with equalness making decisions and then provide behavior change and system change, in all areas we know a lot about what works but a lot of the science based findings are not being implemented in usually care settings as well, and it has been recommended and put resources there in terms of a research agenda.

I think that there is room for really thinking very creatively about prevention, and prevention in late life is not — is in fact possible. It makes sense that has to be thought about within the context of significant co-morbidities and we need to address those presentations, we need to think specifically in terms of services research, integrated service delivery and all of the components and how to do that from a research question, what are the best ways to do it the cost-effective ways to bring together primary care mental health, to help people to age well and health fully in the community, what sort of care management models are important, how do we in fact think about taking people with multiple disorders and have them efficiently provided in the best state of the art care within the community, and then there are a host of research questions around home and community based care in integrated long-term services and cost-effectiveness questions. In the area of basic and translational research, it is wide open, and certainly genetics and disease prevention are very important and promising areas. Individually targeted therapies, based on genetic — are the further you in terms of the shotgun approach, we are going to be tailoring medications to people's individual capacity to respond to medications. Cognitive neuroscience and even neuroprotection, protecting people from the types of disorders that are age acquired are very hot and have huge promise in terms of protecting and enhancing health and well-being in late life.

The final thing that we are looking for the evidence based center health promotion, prevention and self management it includes delivery system designed support around what works they have the research to do that and clinical information systems to back that up within an informed activated consumer and proactive health care provider so we do have that system of care as oppose onned to the cottage industry that was before, finally I think we all want to be at this point, IDA Kline, has a job, an aerobics instructor at age 100, she is sitting down, she has some physical disabilities, but she is leading the pack. And she is still working in with other people at the age of 100, physically involved, and has a terrific attitude about living health fully in late life and is doing all the right things, thank you.

## (Applause.)

GILBERT DEVEY: Now we will turn the pages here, to Dr. Debra Lerner. She is going to address us on the topic of productivity and social engagement. Debra Lerner is associate professor of medicine Tufts university university, receiving her Ph.D. from Boston university, MS degree in health sciences and administration from the university of Cincinnati.

DEBRA LERNER: Hello and thank you all for hanging in there with me. I'm a at a little bit of a disadvantage I think aim missing a slide or two but I will do my best. What I'm going to be focusing on is a little bit narrower than some of the discussion this morning and has to do with the millions of Americans that have work disabilities in relation to having a chronic health problem or illness or an impairment. And many people who have chronic health conditions already have disabled or are vulnerable to developing them, so what we are going to be talking about today, is some suggestions for research programs to sustain employability and productivity of these Americans which we think makes both economic and social sense as the point was made this morning very well by Mr. Sperling. So what we found, a group of us took this on, we all do research in the area of chronic health problems, and employment problems, and work productivity and we said to yourselves after doing after all of this research for years and years what would we want to do that was different, and we started looking at what the safety net looked like for people with chronic conditions who have employment problems or are vulnerable to developing them and what we found was that services in the US to help adults with cope with the work disabilities which we need by a variety of employment problems that arise in relation to the chronic conditions, these services tend to be very narrowly focused and highly fragmented. So it was District couraging, and from that we developed some ideas about research that we think it would be helpful for guiding new progress for programs and policies. So just to ensure that you understand the area that I'm talking about, because it is a little bit different, it is we know now that 100 million Americans roughly have one or more chronic conditions, and because of the aging population that is rise to go 160 million by 2020 although I did see some other numbers this morning, so it is always fuzzy but that is a lot of people. And the number with chronic conditions and disabilities is extremely difficult to estimate and if you go into some national databases, it is really hard to get your arms around this problem and that measurement issue is something that I will come back to later, we know right now from sources from the national health interview is your ray that 10.4 million Americans, roughly age to go 64 years, have at least one chronic condition, and have a work limitation, they are limited in their ability to perform their major activity of daily living which for this group principally is employment.

We know that the work limitation rate for people 45 to 69 years of age, is roughly 3 times the rate of those 18 to 44 years of age. And a survey by Ron Kessler a national survey they found that 25 percent of employed Americans missed one or more workdays in the past 30 days due to a chronic condition or they worked as a reduced level o effort. We did a survey in the mid '90s, this was a survey of people with chronic health problems in which you are trying to measure different aspects of functioning in the workplace and found that one-third of the US sample with a chronic condition had some problems, -- And many of you know he better than I that 1999, 5 million Americans received SSDI, 6.6 million Americans received SSI benefits many people are on Social Security, disability programs, as a result of their health related employment problems. And several studies have been designed to try to estimate what the total cost of work productivity cost lose are as a result of and the closest we have come is \$234 billion annually, and those costs exclude -- it includes abseen seism, premature death or retirement and those sorts of things but somebody brought up the issue here today, which is difficulties people have day in and day out trying to hang in the workplace and find that they can't always do their -- can't always perform optimally in the way they like to perform. I wanted to give you some idea, there have been tremendous improvements in measurement, I think it really hit home for us the problem of workdowns for people who were currently employed, and again, that is at lot of my affects people who have some experience in the workplace, and people who are actively participating in the workplace or have participated at some point, we just finished a study at NIMH study observing people with depression who are currently employed and had no intention of leaving the labor market when we started studying them, we compare people with depression to 2 other groups, a healthy control group, and a group of people with rheumatoid arthritis, and we included that because there is lots of documentation and difficulty functioning in jobs and certain kinds of jobs as a result of rheumatoid arthritis, so we knew this the probability -- we wanted to know where depression really fell into place, so what we found here the first 3 columns are 3 different depression groups and everyone was employed at the beginning of the study had no intention of leaving, all of these people were screened in the primary care office but were in the doctor's office when we found them and we found within 6 months the unemployment rate in the depression groups was roughly 15 percent compared to 3 percent in the arthritis group -- and by the way this was at a time when the Massachusetts, where I'm from went from full employment to having served a economic it in Mary so what happens when the economy turns around we will see what happens to people with depression. You follow people over 18 months and most of those people never regained any employment. If we just focus on the bottom part of the chart here we see that the group that was still employed, through the course of the study, and we saw that there was a decline in hours, even among those who were employed, I'm sorry, among people who were employed, there was a reduction in hours, and a reduction in income in the depression groups, so the vulnerable to all kinds of adverse work outcomes in relation to having this chronic condition.

And finally, I think what was most important to us, even though we looked at some people who lost their jobs and never came back, some people turned over jobs they went to other jobs some of them were out of the labor market for a while, went back in, but overall in a 6 month period in the depression the remainder of those people the remainder percentage turn over so turn over can be an extremely stressful experience in the cases where he found most of these people turned over to jobs that were less lucrative, less hours, less money and we didn't see anywhere near those same rates in the other comparison groups, so that is a little bit about the impact of a major mental disorder.

This is data from the Lockheed Martin corporation. And I work with a lot of employers, and fortunately Lockheed Martin corporation is open about presenting the data, these data were presented in the Harvard business review articles about and we served about 1600 employees here, this is what we call present teaism, this is productivity associated with chronic conditions, just as a caution some of the people in the condition categories can have more than one condition. So these with the major migraine headache which is a chronic recurring condition, is about 12 percent prevalent in the sample. It is roughly a 5 percent productivity loss for people who go to work, not people missing work or people on disability, but people going to work that suffer from migraines, and the annual aggregate lose has to do with the prevalence and cost per individual, even for people who are trying to hang in there who have various kinds of chronic conditions there is an adverse work impark, and something that fortunately has been attracting the attention of a large number of employers in this country. This is the last slide, again from the depression study that I thought might be important to show you here, because here what we did was we took if you look at the two bottom lines on the graph, you see again the health I didn't control group over an 18 month period so you see where they are ever 6 months in the study and along the Y axis you can see the percentage of productivity lose associated with that group.

And then we took our depression groups and we decided them into 3 groups, the group that got worse within the first 6 months in terms of their depression, a group that basically stayed the same, and a group that according to clinical definition was improved to so the depression got better, what we find that was important, is that if you compare that red line there, let's say to the healthy control group, what we find is that even with treatment, this is usually care treatment, not the highest quality treatment but the kind of every day treatment we would get in the doctor's office in Massachusetts, that a group that is clinically better is functioning nowhere near our comparison group so this is a real policyish from you the standpoint of the employers and the employees, this he are in a contest where they know they are not performing as well as they might have performed before they got sick, or as well as some of the average workers there, so even with medical care, this tells us that even if you provide people with medical care, and let's say we can get that gap closed with excellent medical care, there is still going to be a gap there between people with chronic conditions and other people, so what do we do about that, well our way of thinking is that you have to develop new models that go outside of the -- that is where you see the big gap in the opportunity as we say for doing something new.

So my colleagues and I, have copies of the slides, I think you can get them or a copy of the paper we can make that available to you. We didn't look at the different types of programs and services that were available for working age people with chronic

conditions, who might be experiencing employment problems, or are vulnerable to developing them. And really, in the US there is sort of 3 sources of health, 3 major sources one is the medical care delivery system, the other is the employer, and thethird would be government programs, and again this is summarizing a whole lot of material that is in a paper that I would be happy to provide you with. Now just to give you an idea of how many people go to the medical care system for chronic health problems, something like 30 to 40 percent of doctor visits for working age people is for the management of chronic health problems and it is probably larger than that because usually things like mental disorders are not counted properly and those are chronic problems in most cases.

So a great deal of the time of the physician is spent seeing people for chronic conditions. What is sort of alarming about the whole thing, I guess what we would call sort of the disease focus is the narrow disease focus of medical care, although there has been attempting to change that it hasn't been successful. So what we would like to see ideally is that the medical care system does what it does best which is attending to people's illnesses but also to and symptoms but also to attend to the functional problems that people have, and problems, for example, of employability, and employment, and we don't see that happening except in the kinds of experiments, and good situations that we heard about in the prior speak eers so for example in the 1990s, we did a survey, and we found that 60 percent of people who had been to the doctor recently, rarely or were never asked about whether they can perform their activities of daily living, which is very discouraging. In our studies of depression, we found these are people who are in the doctor's office who are currently employed, experiencing problems, and only 20 percent of them told us that the physicians ever asked them about work, and given them my advice about work, so there is a tremendous gap there. There is also a gap when you look at health care spending, it is primarily at direct cost of medical care, such as medications hospitalizations, doctor visits and so on and a very small proportion of spending goes to transportation rehabilitation services and the like, so this kind of imbalance hasn't changed very much recently. And it is unfortunate because what you see in the medical care system there is a fairly large evidence base that tells us that some of the deter – are social in origin, so for example there is a great deal of literature in thearthritis area that tells us that certain characteristics of the job such as autonomy on the job are important to improving the employment prospects of people with arthritis, similarly found characteristics in the workplace that are important for people with depression.

But somehow those kinds of pieces of knowledge, don't get integrate nod the routine care of people with chronic conditions, so this remains sort of a big gap that we haven't been able to fill. Secondly, our employers, and most of us probably are working in the room here, or have some experience with a spouse or a family member that works, and we know that employers are primarily service brokers. They sponsor insurance, they sponsor you heard about from Ken this morning, that there is medical insurance, there is Worker's Compensation, there is disability insurance, in addition, they administer benefits like the family medical leave act, and so on. In addition, since the rise in health care cost beginning in the 1970s, many employers have gotten into the business of providing services directly or bringing in vendors with services in a whole range of areas. The problem that we see with the employers, while there is some wonderful things going on in the workplace, some really creative things that employers are trying to do to prevent the onset of chronic conditions and certainly to prevent the loss of productivity in the employees, most employer services remain pretty SILO focus. It gets used a lot these days but it does make sense for the employer world, one of the biggest problems in the employer world is the distinction between occupational health services and nonoccupational health services so if you have employment problems related to a health problem that is occupational in origin, you end up in Worker's Compensation where you get some income support or medical care, it is not ideal obviously and there is a small range of conditions that qualify to to come under that umbrella but there is focus on return to work and employment. For people have problems nonoccupationical there is medical care, and if you can't work, you made end up on disability insurance so for that large group of people that are in the middle that we talked about earlier that are having some problems functioning at work that are hanging in there, trying to go to work every day if they can, with eye is really the majority of people with chronic conditions, it is really -- there is really no services except for traditional medical care. So that remains another large gap in our safety net. And I won't say very much about the government sponsored programs because there are many experts here this morning who know much more than I about this, but I think the important thing is that many of the programs with the Social Security programs do, and they are not particularly question signed to keeping people on the job at all, but certainly not even getting them back to work, that remains a tremendous challenge for the Social Security system, vocational rehabilitation services, while extremely valuable have gotten narrower in their focus over the years, and tend to focus on the severely impaired populations, and first employment, getting people into the job market for the first time, or into a new area, job training programs that are government sponsored rarely deal with people with disabilities, they don't provide those kind of services and when they do again it is usually oriented towards first time labor market entry.

The only piece of legislation program that seems to have some emphasis on job retention is the ADA programs and particularly the job accommodation clauses, and unfortunately, what we know from the ADA is that it has reached too few people, and the evidence seems to suggest that people don't make use of the ADA, and when the accommodations comes often too little, too late, so the program hasn't been having the reach that it might have to this potentially large group of people, who have chronic conditions. Am I done?

# GILBERT DEVEY: Yes.

>> I was just going to say that there are a number of suggestions we can make in terms of medical care. There is a lot of evidence that shows that multidisciplinary provider teams are effective in reducing some of the functional problems of people with chronic conditions. It hasn't been applied to our disability yet. We know that health professionals such as occupational

specialists, rehabilitation specialists have knowledge of the workplace and could be applied more effectively to this group as well. There is a fair amount of evidence that is accumulateed that self-care techniques are veil you able for people in terms of restoring functioning, and keeping people functions for periods of times, and we need to identify those strategies that help people retain employment. And again, I will mention the uptake issue. I won't go over the employer sector except there has been great innovations disability case management disease management that have not been orient towards keeping people in the workplace but certainly could be oriented towards that, we have a problem with employer strategies, they have low participation rates of employees and we need to understand methods to get employees to go into those programs so that their confidentiality is protected and there is a huge literature that you a ton nonhe on the job, psychosocial demands are important to people's health and functioning and we need to know more abouthow we can modify characteristics of work organizations to keep them there, and I'm going to end there.

## (Applause.)

GILBERT DEVEY: We moved along now, and we are going to hear about economic security, from Dr. David staple ton, who is an economist, and directs a Cornell University institute for policy research here in Washington, D.C. his research focuses programs for people with disabilities, and especially their impacts on employment and economic independence. Dr. Stapleton.

DAVID STAPLETON: Thank you. I'm very pleased to be here, I'm pleased to see so many people are around after a long day of exciting speeches. My topic is transforming economic security for people with disabilities, and there is some background material listed here thatsome people may be familiar with including the top item which I have some copies on out on the tables outside. And what I'm going to do is first talk about what I think we have learned from the last 20 plus years of research about what we need to do to transform the way that we provide security to people with disabilities. And I'm not going to tell you about the research. There is not time for that but I will tell you what I think we have learned and then I'm going to tell you how we can do it in the next 10 years. At least the strategy for doing it.

What we know from the last 20 years research, I think that we know that there are many working aged SSDI, and SSI beneficiaries who could earn more from work than they do. Probably millions of such individuals. Out of the 9 million roughly beneficiaries of the working age, now for many of these people, substantial work would be a significant and unreasonable -- we would not expect them to do that to support themselves. But there are many others who have are not working because of work disensensitives, and because the support system is such that it deters work or makes the work too difficult. And in fact, even more there are people who perhaps could not work now but if we had the support system in place when we first -- when they first had a disability or became an adult after child onset of disability, they could also be working.

I think we know that. I think there is millions of them, and I think their potential earnings are very large. What about the work disincentives, I think you are all probably familiar with many of these if not all of them what we call the SSDI benefits, which I will not bother to explain. For SSI if you have earnings you can earn something to keep your benefits, but for every dollar you earn, you lose 50 cents. Imagine somebody working on SSI paying a minimum wage, and there's about \$6 an hour or so and we basically tax them \$3, all right, so they are now working at \$3 an hour, what kind of incentive is that, that is a higher tax rate than we charge Bill Gates. Medicare and Medicaid eligibility are linked to SSI and SSDI, we are taken steps to review them but we are starting on that process and there are lots of benefits that are somehow linked to what you earn and tend to go away if you earn too much, foot stamps, housing subsidies, Worker's Compensation, private disability benefits, et cetera.

Lots of work disincentives. The support system is inadequate. We know that. We know that it is incredibly complicated. We know that it has an antiwork bias and we referred to some of the antiwork biases in the support system today, we also know the consumers often have very limited options and control. It makes me wonder why anybody would work under these circumstances. Walter -- says disabilities steel time, to my mind, our support systems steals even more and the very people that need the time the most. We heard Dr. Giannini this morning, she shared a quote with us, and I want to be sure I get it right here, when spider webs unite, they can tie up a lie LION, I think she applied it in a very good circumstance, but I take it to our support system, I think our support system ties up people with disabilities because it is a tan gelled web and that is a major impediment to work, is self support. In the past five years or so we have done some research that proves pretty clearly that the employment of people with disabilities is not only low but it has actually been declining for about 15 to 20 years. It is somewhat controversial and difficult to measure but I think it is quite conclusive on that subject. The causes of the decline are unclear. Some people thought and some people still think that the ADA actually contributed to the decline by putting, mandating accommodations for e-mail employers but there is new evidence that firmly rejections that hypothesis and I think we can dismiss that as the cause. There is also evidence that declines in incentives to work or increasing disincentives to work have caused the decline or contributed and I think that evidence is much firmer at this point, irregardless, employment is very, very low, we can also determine from looking at statistics on income that people with disabilities really do not benefit like the rest of the population from the great economic Boone that we had in the late '90s, while the incomes of other people went up their incomeses were stagnant, the percentage that lived below the poverty level actually improved a little bit while for other people it was declining. We also know, and you don't need research to tell you this that the support system that we have, the economic security system we have for people with disabilities, is out of step with the Americans with Disabilities Act. It is out of step with the rehab act. It is out of step with idea. Those pieces of legislation look for, including people with disabilities in mainstream activities, and promoting their independence and participation in all social activities including work.

In fact, what our support system does is to encourage dependents. It is also out of step with advances in the understanding of disability from the scientific social science perspective. We have gotten rid of the medical model. We are on to -- we understand now the parole that the environment plays in determining whether a person's medical conditions result in a disability. Now I was very pleased to hear the speaker from SSA this morning publicly acknowledge that the definition of disability that we use for the Social Security programs is inconsistent with our understanding of what a disability is and needs to be changed.

The support system is also out of step with advances, the great advances some of which we have heard about today in medicine and technologys that have occurred in the past 20 years. There are lots of things that people with serious medical conditions and impairments could do that they couldn't do before. We are not taking advantage of those things because of the way the core system is set up and because of the disincentives.

Expenditures on disability support are very high and growing at a rate that is faster than the rate of growth -- other federal outlays. In 2002, we spent 226 billion dollars on supporting working age people with disabilities. That is just federal expenditures. That is 11.3 percent of all federal outlays in that year. It is 2.2 percent of the GED. 70 percent of that was spent for income support and health care, and 75 percent supported health care of the 8.7 million SSI and DI beneficiaries of working age were about \$20 per beneficiary. We also spent about 50 billion dollars in that year with state governments, on federal state programs and this doesn't count the state only programs and we don't have a number for that. Since 1986, federal disability expenditures have grown much more rapidly than total federal outlays or gross domestic product, 6.1 percent of GEP, in 1986 to 11.3 percent in 2002. Almost doubled. The 1.4 percent of -- I'm sorry that should have been federal outlays. 2.2 percent of GED. We also know that the economic security system for people with disabilities is on a collision course with what I call the deficit bus. The fact is driving our large federal deficit are only going to get worse as the baby boom generation retires, disability expenditures are growing faster than outlays we are hearing discussions about cutting Medicaid and cutting SSI benefits and that is now and it is going to get worse. It will be incredibly painful because the only options that Congress has at the moment are to tighten eligibility for the support programs that people with disabilities have come to rely on especially the income support program, and the medical programs. Tighten eligibility, or tighten the value of the benefits. The support or the medical care that they get.

So that is a pretty bleak picture. Against that, bleak picture I wanted to describe what I see as an opportunity for a win/win policy change. It is not one that we can do easily. It is not one that we can do overnight, but I think this opportunity is there. The premise of this, is that there is some change in program design that would make people with disabilities who can work better off, and it would increase their economic security, not reduce it. And it would reduce the growth rate of government spending, reduce the growth rate of government spending on people with disabilities of working age. The resources such change would require would come from two places. One is the great underutilized capacity of people with disabilities themselves. They are capable of providing much more support for themselves, some of them are at least, than they do.

That is part of the premise. The second is the waste of the current support system. It is very inefficient. It doesn't give people with disabilities what they need in a much more efficient system would not only provide better support in helping people work but it would be less expensive to operate. What it seems we need to achieve in this windowpolicy is a new workbench fit that would provide economic security in a different way. It would provide it by making work pay for people with disabilities who can work, and it would provide it by fixing the support system for people who participate in this program. There are many challenges going forward to implementing such a program. First one is if we develop such a program and just put it in place let's say next year and apply it indiscriminately we do tremendous harm to people, people who did not expect to contribute substantially to their own support, why is that because we can't tell who can. No administrator can go in and say you can support yourself, you can't do that, we don't have the means to do that, and don't know how to do that. It would be too expensive probably even if we did

The second problem we face is that the support system, is provided to us by many different agencies. History and the competing interests of these agencies suggest that they at the federal and state level would have a very difficult time cooperating to develop this new support system despite the co-op participation that was evident in the discussion from the previous panel. I think this is probably one of the biggest understatements made today.

## (Laughter.)

DAVID STAPLETON: So I won't elaborate. So let me describe what I think is a 10-year strategy that we can pursue in this country to develop the type of system. We have to try to wrap up, okay. So I'm going to just fly through this. I believe that the way that we can launch demonstration in the next 1 or 2 years of a work support system or maybe several different demonstrations of work support system that would be favorable to many people with disabilities. Get large numbers of those eligible to work, without hurting the populations who would not want to be involved. And the -- this slide outlines those, and because of time limitations we will get you a copy of the slides if you want it and you can see it up there. There will be opportunities I think to discuss this in the follow-up sessions later on. I will just mention what I think is one of the most promising is the benefit offset, that the Social Security is designing, and they seem to be quite interested in really making this a very gold plated demonstration in terms of providing work support for people with disabilities. The -- so we can get that going in a couple of years, I think. And we can get several of them going, different demonstrations and then over the next 3 to 5 years, we spend some evaluating them, improving from them, learning from them, building confidence support solid filing them, we can continue this that vein over years 6 through 8 to expand these programs so that they cover broader populations in more states,

beneficiaries from other program, besides the ones that were initially addressed perhaps, expand the gateways and entry into these programs, develop additional improvements and adaptations as we expand the population covered, and build public confidence and support that we actually know what we are doing and can do something positive, and then in the last couple of years, we would be in a position to enable legislation that would do a lot of good and put things in place, I think a new program is well designed to become a gateway into the program, I think the traditional programs, that is people couldn't succeed in the new program, the traditional programs would still be available. I think the traditional programs could also be simplified because when you get rid of the work incentives and other efforts that are sort of attached to these programs which we are trying now to do a job that it is not up to doing.

And at the end of 10 years, Congress would have a better option than simply cutting benefits for people with disabilities, when the budget deficit bust arrives with a vengence, they have an option of encouraging more people to use a less expensive program and providing more support for themselves. Let me quit there, and I hope that people will stay around for the follow-up sessions and I would love to be able to discuss with you some more.

## (Applause.)

GILBERT DEVEY: Now we turn to technology universal design and environment. To be presented by Dr. Greg Vanderheiden who is professor in the industrial and systems engineering department, mainly the human factors program and the biomedical engineering department, R&D center at the university of Wisconsin Madison. Greg Vanderheiden van thank you, I have a research agenda but I'm not going to tell you what it is. I think that it is more valuable to provide an idea for what technology can do to stimulation than it is for an engineer even one with human development gear ontology background to try to tell you what technologies you should have to solve the problems of people who are older. So I would like to talk about is problem based research versus technology based, or technology driven. And I wanted to just walk through and give you a little bit of an idea for the kinds of things that can be done, and to try and expand your thinking, and then to challenge you to think about technology in a different way. And that is, by not thinking about technology. Think about what it is tha would help, what it is that the problems are, and what kinds of things could be used to address them.

Now, we have all seen disability as a function of age and we see that as we age, the percentage of us having disabilities shoots up. Another way of looking at it is to pick one of the people on the screen, the people who are red have disabilities. So if you can pick someone, and you can sit and just watch and see what happens as we age, and as you can see, we either end up with a disability, or everyone around us does. And so we either have a disability to contend with or we have to take care of somebody around, friends, family or we lose friends and family who disappear from our midst because of disabilities preventing them from being able to go out and be out with us, and if we look we can see that the kinds of things that are happening, arthritis, about your situs, visual impairment and hearing impairment and the 50 percent that is big, so as we head up there we start hitting, and we are hitting multiple disabilities, not getting pure disabilities so how are we addressing these, so technology to the rescue, the question is technology going to solve the problem or is it causing the problem? Of course, it is neither the solution nor the total cause. But it can contribute to both. The solution and the cause, technology can make things a lot more complicated, microwave ovens, do you remember when a microwave oven you turned to see what you were doing and you punched a button, I was on a plane and he was with multiple corporations he headed up, and he said he and his wife decided to get a new microwave so she took theirs down to goodwill, they went down and bought one and brought it home and they couldn't figure out how to use it and they went back and sat there in the store with the salesman, and he showed them all of the microwaveness the store and he went back to goodwill and they bought their old microwave back.

# (Laughter.)

>> That is great. What if the old microwave broke? How many individuals, you have stoves, we have a real problem with stoves, older people's stoves, people who have visual impairment stoves, and they are not just not safe anymore and you can't find another stove that they can operate, a lot of them you have to have buttons and dials, and they work on displays and if you can't see them, you can't use them. We have phones, you know, phones used to be really neat, you picked them up and dialed, you feel the dials even, and now you can't figure out how to use them. Somebody says, you have a phone here is my cell, and you go, how do you use it? And my favorite quote, is the fellow who said I always wish that my computer would be as easy to use as my telephone, and my wish has come true. I no longer know how to use my telephone.

# (Laughter.)

The author, is the person who originated the C++ program language. Okay. So don't feel bad. You are in good company. We are not in the bottom half, okay, when we are not even in the bottom two-thirds, or bottom 3 quarters, keep going up, and you start hitting where we are. And if we have trouble with all of this stuff, what about everybody else? And what about us pretty soon? But it doesn't have to be that way, it is all a matter of interfacing, technology can make things simpler, take the VCR for example, the poor may lined VCR, we have these things and how many people, I actually know somebody who went and they chained the alarm clock to go off so that it would remind them to go manually push the record button on the VCR because they wanted to record a show, and they didn't trust their ability to program their VCR. And I see lots of heads nodding. That is very sad. But the technology is there. Especially when the odds of getting your alarm clock setback are equally as bad, and that is really bad to risk resetting your alarm clock.

The research that we are working on and let's say Iwant to record a show, so let me, when is Chinatown on? Oh, it is on twice. 7:00 p.m., I want to watch something else then, 1 a.m. that is pretty good, so record chin may town on Sunday. And it is recording. Okay. Or I could say, what time is king KONG? 7:00 p.m., recording, and it is recording, or you can do it easier, you can walk up to your thing and say, record FRASIER tomorrow, and bingo, it is recorded. So that kind of a capability, this is already here. We have this kind of capability. All right. And we are now working on developing it and making it more and more robust so that people can say, show me the 9 ears. And it will turn on the 49ers. So that it can actually handle really diverse. The impact for everybody in the room is saying, how do I get that?

#### (Laughter.)

And I say but you have to type, and you say I don't care, if I type in it will do what I want I will type it. We actually have a demonstration coming up where you can actually take your cell phone and you know you just send a message to your thing, and it will record it. So you just send the message, and so you are out you go record such and such bingo, it is recorded. This is possible, okay. You say, that is not possible. It is possible, and there's many places working on natural language some of them trying to make sure that it will understand anything which is a great scientific endeavor but there's simple little things like this. How about going to the thermostat saying can you set it down 2 degrees and it will turn down, I mean there is things that we can be doing, figure out what it is that is causing the barrier. Some day you could have an individual that just sits there they look down and grab a little cell phone, set the coffee maker to 4 a.m. so you have some coffee tomorrow, and when you get up at 4:30, you are going to need it record the news on channel 4 and turn the house alarm on, sets the VCR, the coffee maker, and the house alarm and they fall to sleep, again these kinds of things, think about it. This is a web server, do you know the worldwide web, this is a web server that is smaller than a PEA. And this slide is 8 years old. Okay.

So the -- remember the we all end up having the plumbing checked and they take the ROTOROOTERS well they now have it in a camera, and you swallow the capsule that transmits the image as it goes through and it take it is whole system and no ROTOROOTERS but it let's you see places that you continue see before. Voice technology, as we start losing our vision and the ability, if we can, -- I will turn this one down. This is -- this is a birthday card for people our age it says at last a talking action figure for people our age and when you open it up it says. Oh, my back, oh, oh, oh, man, I got to lay down.

#### (Laughter.)

That is a real life card and it cost \$3.99. People it used to be that adding voices to stuff was expensive, \$3.99 it has a speaker chip, a battery and cost 50 cents more than any other card on the rack. The world is changing and this wasn't special. There is a whole bunch of things, and there are new ones out. It just doesn't cost what you think it did. The world is not the same. We can't get used to it. So don't try to think about what technology can do. You can imitate technology and have it read to you. This is a computer a little chip, reading the text. It just took a newsletter and fed it to it and this is what it says., technology report -- and commentary on the innovations and contemporary computing and the growing number of technologies, and -- a world of exponential technological growth. Okay, so, the old machines that are mono tone are gone as well. Here is a virtual keyboard, and it project as keyboard and you type on the image and it will act like you are typing onnen a typewriter, and you say who wants to type on a keyboard like that. But how about the little thermostat, you have a thermostat and you have great big letters on it the person walks up and everybody can use the thermostat like normal if you can't see you push a button and it throws an image on the wall below and now you have a control panel this big with numbers this large, and you can see it and you use it and when you are done it disappears again so the accommodation is there when you need it and it is completely invisible the rest of the time, think, what would -- just go crazy. Because people are figuring out how to do it.

Had here is one where they actually have the ability to look output a pair of glasses on and that is all in Japanese but you can have it so that what you see is the translation superimposed on it. So you can have large print superimposed on small print whenever you looked at something, you scratch your temple and suddenly you have this magnifier on the glass in front of you. It would be great to from the telecommunications they keep losing it this is a jacket that has the phone built in it. You put the coat on and is right there, and when it rains it is built into the collar, almost like beam me up SCOTTY. Here is one they are actually working on WEAVE it into the shirt, he put the T-shirt on goes out running his heart starts doing flipping around so the shirt contacts through the cellular, the satellite, the doctors monitor and call the doc over and say hey look, they call an ambulance and meet you a at the corner and say hey you are going to have a heart attack in 5 minutes, would you like a ride? I mean, these things, this is what is out there. There is actually, these are things that are moving into the commercial applications and things. Again, don't worry he about if it is possible, pretend like it is. Okay, this is a piece of paper, you print on the paper an fold it up it is a cell phone, cheap, you give tones to somebody and they lose it who cares, as long as you turn off the service, this is a cell phone you flip it open it says what do you want to do, and you say call somebody but you can say call 689-394-2874 and it will dial the number for you. Expensive phones right, \$29.95, with a two-year subscription. And it was done in a phone was on the market for a year they changed the software in an old phone, and it doesn't have to be technology, it can also be services you can have assist answer on demand you take out your phone and say I won't be home in time record, or play this, or turn on that so that you don't have to figure out how to operate the things, or you can say what is this? And they have cameras and things or you can say read this to me, and so you get somebody who is out and they see this up and they can't understand it or they say explain this, or where am I, or where can I find such and such? Or how do I operate this? Have you ever been faced with something that you wished you could grab your phone and punch in and say how does it work, these are all possible, and if it would -- so why doesn't technology feel friendly to seniors? Why does it scare us? It is designed by people who can handle or thrive on complexity but that is part of the problem, most of it is our own fault, we buy products with the most features and then we complain with the

complexity. Have you ever been in the store and you look this one has the little list, a big list which one do you buy? You get home and you software and curse at the thing because it is so complex. They are only going to make one later with a longer list, - there is very little research on what seniors can use, the research is driven by technology, or what is cooling cool. It is just is, it is the way it is, and Dr. Giannini this morning was talking about I used to serve on the research program that she shedded at, and one day we were sitting there and we said we get these proposals for laser things and high technology, how come we don't get stuff for the long cane, okay, the long cane is so much better technology, fundamentally, useful, and I just looked on the table, and I said, right. You award \$500,000 for somebody who wrote a proposal that said I want to study about waving a stick in front of them as they walk down the street, before you know about a long cane, it sounds like you know, either pretty silly, I mean you can wave it around, or it sounds pretty crazy. So what we really need to do, however, if you talk to the blind people you come up the other way they would say I would much rather have research on better composites better which to get more feel and handle from what is happening at the tip than I would about carrying around something that weighs 10 pounds and I have to charge every night. We need to get there.

So we need to start with the problems and not technologies. It is not the problems that lendS THEMSELVES to technologies either. Don't think okay, what kind of technologies, these kind of problems are technology problems that is hammers looking for nails. Don't do that. Rather take a look at what causes seniors to suddenly stay in, to slow down, to sit down, and to decline. That is a real pattern. Why does it happen? Is it confusion to transport they went out and are confused now afraid to go out is it fear of confusion, a friend of theirs went out they are afraid to go out. They can't match colors? We found when we went out looking we found straining things. One GAL did not ever go out again after she went out one time and heard her friends commenting about her mismatched clothes. Older, you say older and you go, well, what is technology going to do about that, forget technology, maybe nanotechnology, maybe chemical technology, don't worry about it. Figure out what it is that caused those seniors to stop going out and then say if we can get over that, and then go talk to nanotech, talk to the people, figure out, I think we need to talk about grand challenges find out what causes problems for seniors, gets engineers to address it and I think we should award grand prize he is to the toughes so lucks to the problems like we do in every other science field, we have tremendous resources, and why don't we focus 5 percent of our nonmedical technology research budget on nonmedical technology that would address some of these problems, these massive problems that we have. So now, why do seniors decline, why don't -- why do -- while others do not why do they suddenly do it. What puts people in nursing homes these are the questions that you need to be looking at. And again don't think about what technology can do, assume you have magic at your disposal. And work from there. Okay. Technology won't solve the problems of aging but it can solve the problems that enable solutions. If we start with the problems, and not the technologies. So in closing, as you go forward in the technology section, think what would I like to be true? What would I like to exist? What would really help if only it were possible? And don't worry he about if it is possible. That is somebody else's problem. Because the people who solve those problems have no idea which problems to solve, and so you will find technology gifts working on silly things instead of -instead of the really tough problems, thank you.

(Applause.)

## GILBERT DEVEY:

# BILL THOMAS:

GILBERT DEVEY: Our next speaker is going to address the issue of positive messaging, but I didn't hear much negative just coming out of Greg. But let's see about Dr. William Thomas and his positive messaging. Excuse me. Dr. Thomas is an international authority on gear rye at trick medicine and elder care. And currently serves as president of the centers for growing and becoming. A not for profit organization, dead dated to promoting and developing constructive wholistic approach to aging as a care for our elders. I'm glad to know you. I may need you sometime. Thank you.

BILL THOMAS: I just want to start off with the technology question I need right now which is what are we going to do about these seat cushions? WHOA, let's call in lance Armstrong on that one. I look at this topic as having two parts. There is in research there are questions and answers, and as I have been here today and listening to the speakers and so on and so forth, I have been just overwhelmed by the quality and the depth and breadth of the answers that have been offered here today. It turns out, however, that my chief research concern is questions. And interestingly, although answers can be derived in a technological fashion using rationality and the scientific method, funding the right questions is a different thing. The right questions come from an examination of biography, and history, sociology, music, art, poetry, literature, movies, books, advertisements. The questions we need are available to us all around us but need to be distilled from the stream of raw experience that comes into our lives.

And so the first thing I wanted to say is as a question seeker, much more effective, I am, than as a question seeker than an answer finder, but as a question seeker, the first thing that comes to my mind is holy cow, we have got a problem, when my topic is positive messaging. Oh, oh. Right there, it tells me we have got a problem. I regard straight up, the aging of America and the broadening and deep penning inclusion of people living with disabilities as signs of manifold success. As signs of a civilization that is starting to hit its stride. And the aging of America from my point of view is not an exercise in determining how best a compassionate nation can burden themselves with all of these old people. With all of these disabled people. How best is our society to carry that burden into the future? That is the usual question, and there are lots of ways of looking at that question. I have got another question, what I want to know is what are old people for anyway?

They are here, they are right here in this room. This they are all around there is more of them every day and I'm pretty sure they are not arriving from Mars. What are they for? In my question seeking, I see older people, and people living with disabilities sharing the come TRAIT that they are living in a kind of fruition, a kind of ripening, a kind of being, a way of living that is so often cut off and lost to those of us who are trapped in that silken web of adult striving, adult oriented busyness, doing, getting, and having. Somehow elders have learned to live beyond adulthood. And how are we to harvest the richness, the breadth, the depth, the value the meaning, the legacy, the worth, the integrity, the grief, the sorrow. The obstackes surmounted that they hold within themselves. That is the question. So from my point of view, when I am kind of looking at this seeking solutions, what I'm actually interested in is how do we make most effective -- how do we turn the aging of America to the greatest benefit to people of all ages. And again, with -- in the spirit of understanding you have been sitting in those seats all day, I'm going to close with one brief idea. A concept that I have been working with, that helps me think about aging, and disability as assets, as benefits, as resources in our society, which we have yet to learn how to make the best use of, this concept I have been working on is something called the elder TOPIA. ElderTOPIA. It is what human beings have been striving for since the beginning of time. Every person who has a chance for a meaningful life wants to live as long as they can. And that means an aged society is an Apex of achievement. Why? Because a society that learns how to help elders give to the young, and the young to give to elders, that strengthens and enriches the exchange between generations is a better healthier society. And that aging, including the disability and physical changes that come with aging, including people who are younger in younger age groups but are living with disability, all these people taken together represent something close to a national treasurer and I wouldn't change them for all of the gold that they have buried at Fort Knox. They are valuable to us, and we must learn how to recognize that value. Thank

## (Applause.)

GILBERT DEVEY: I have enjoyed listening to these great folks talk, and it was fun. I thank you all very much. And I hope you all in the audience will put them to the test of the questions and answers that will be the reason for having the next session. Thank you all very much indeed.

MR. CASHDOLLAR: Ladies and gentlemen, thank you for your presence here, and your attention,.

WINTHROP CASHDOLLAR: As you well know, we are a little bit behind schedule but what we would like to do, is send each of our participants to their policy breakout sessions. We will have the reception ready for you when you come out of that. We would like for you to at least touch base with the coordinators and others who are running your current policy breakout sessions today and tomorrow, and so if you haven't already noticed there is a number on your badge, or should be that divides you up into different groups according to the preferences you told us about. So what I suggest is that people go from here, immediately, to their breakout session rooms, and work through 30, or 45 minutes of preparation, and let us hit the ground running tomorrow. So just briefly, if your badge says session 1, that is social engagement and productivity and that is just a short distance down the hall, if your badge says section 2, that the healthy living that is 1 A down the hall, and if your badge says session 3, that the economic security, and that is in salon C down the hall, and 4 is technology and universal design that is in the crystal room at the end of the hall, section 5 is positive messaging in the board room which is halfway down the hall. Thank you very much. And the reception will be in this room as soon as we can get it set.

# CRYSTAL CITY MARRIOTT, MINI-CONFERENCE OF THE

## 2005 WHITE HOUSE CONFERENCE ON AGING

JULY 22, 2005

(MORNING SESSION)

ANDREW IMPARATO: GOOD MORNING, EVERYBODY. WE ARE GOING TO GO AHEAD AND GET STARTED. PLEASE TAKE YOUR SEATS. I AM A MEMBER OF THE PLANNING COMMITTEE. WE WANTED TO START THIS MORNING BY SHARING WITH YOU PART OF THE PREPARED REMARKS THAT SENATOR BROWNBACK WAS GOING TO GIVE US YESTERDAY. THOSE THAT WERE HERE REMEMBER HE WASN'T ABLE TO GIVE HIS REMARKS BECAUSE HE GOT CALLED TO A VOTE ON THE HILL. HE HAD TO GET RIGHT BACK. BUT I THINK SOME OF HIS IDEAS MAY HELP US AS WE GO INTO OUR BREAK-OUT SESSIONS TODAY. SO I AM GOING TO READ JUST A LITTLE BIT OF WHAT HE WAS GOING TO SAY YESTERDAY. AGAIN, THIS IS SENATOR SAM BROWNBACK OF KANSAS. AND A MEMBER OF THE JUDICIARY COMMITTEE AND DEFINITELY A RISING STAR WITHIN THE REPUBLICAN CAUCUS AND THE SENATE. SENATOR BROWNBACK WROTE IN THE CONTEXT OF CHANGING PUBLIC POLICY, WE MUST EXAMINE -- MEDICARE AND MEDICAID ARE SERVING THE NEEDS OF INDIVIDUALS WITH DISABILITIES. FOR EXAMPLE, THE MEDICARE PROGRAMS BENEFIT MORE MOBILITY DEVICES HAS IN THE HOME RESTRICTION ALLOWS THEM TO DEVICES NECESSARY WITHIN A PATIENT'S HOME. UNFORTUNATELY, THIS DOES NOT ADDRESS THE NEEDS OF A PATIENT WHO WOULD USE THIS DEVICE TO OBTAIN ACCESS TO HIS OR HER COMMUNITY, WORK, SCHOOL PHYSICIAN'S OFFICE, PHARMACY OR PLACE OF WORSHIP. IN VIEW OF THIS, I RECENTLY SIGNED ON TO A LETTER REQUESTING

THAT MEDICARE'S MOBILITY DEVICE IN THE HOME RESTRICTION BE MODIFIED TO IMPROVE COMMUNITY ACCESS FOR MEDICARE RECIPIENTS WITH DISABILITIES. ALONG THESE LINES, CONGRESS MUST ADDRESS THE ISSUE OF ACCESSIBILITY TO LONG-TERM CARE FOR THE ELDERLY AND THOSE WITH DISABILITIES. CURRENTLY WE HAVE A MEDICAID SYSTEM THAT SPENDS APPROXIMATELY 2/3 OF ITS DOLLARS ON INSTITUTIONAL CARE AND APPROXIMATELY 1/3 ON COMMUNITY SERVICES. THIS ANTIQUATED POLICY

EFFECTIVELY REMOVED ELDERLY INDIVIDUALS FROM THEIR COMMUNITY, FAMILY AND FRIENDS. EVEN FROM A COST PERSPECTIVE THIS SYSTEM DOES NOT MAKE SENSE. ACCORDING TO THE NATIONAL ASSOCIATION OF INSURANCE COMMISSIONERS THE COST OF NURSING HOME CARE RANGES FROM \$30,000 TO 80,000 PER YEAR WHILE ANNUAL COST OF HOME AND COMMUNITY CARE IS LOWER.

THIS IS SENATOR BROWNBACK'S REMARKS. THE BOTTOM LINE, CONGRESS MUST ALIGN THE MEDICARE AND MEDICAID PROGRAMS WITH THE GOALS OF AMERICANS WITH DISABILITIES ACT, AFTER ALL WE LIVE IN AN AMERICA -- WE LIVE IN AMERICA, IN THIS COUNTRY WE CELEBRATE INDEPENDENCE SELF-DETERMINATION UNIQUENESS AND A SENSE OF COMMUNITY. I JUST WANTED TO SHARE THAT. WE ARE GOING TO HAVE COPIES OF IT ON THE MATERIALS TABLES AT LUNCH TODAY, AND WE ARE ALSO GOING TO PUT THE FULL TEXT OF HIS REMARKS UP ON THE WEBSITE FOR THIS CONFERENCE. I AM GOING TO TURN IT OVER NOW TO THE CO-CHAIR OF OUR PLANNING COMMITTEE, MARGARET CAMPBELL. THANK

YOU.

MARGARET CAMPBELL: GOOD MORNING AGAIN ALL YOU GOOD PEOPLE. IT'S WONDERFUL TO SEE SO MANY HERE AFTER A VERY LONG DAY ON WHAT WE KNOW ARE LESS THAN COMFORTABLE SEATS. BUT THIS IS WHAT IT'S ALL BEEN BUILDING TO. FOR THE PLANNING COMMITTEE, CERTAINLY ALL OF THE MONTHS OF PLANNING, BUT FOR YOU ALL, THE PARTICIPANTS, ALL OF THE INPUT THAT YOU HEARD YESTERDAY AND THIS IS WHAT IT IS BUILDING TOWARDS, TO NOMINATE A PROCESS AND FINALIZE THIS LIMITED NUMBER OF PRACTICAL, REASONABLE, AMBITIOUS AND ACTIONABLE RECOMMENDATIONS ACROSS THE 5 CONCURRENT SESSIONS THAT REFLECT THIS AGING WITH AN AGING INTO DISABILITY THEME THAT WE WORKED SO HARD TO BUILD INTO THE VERY SINEW OF THIS CONFERENCE. THIS IS VERY IMPORTANT WORK. AND WE HEARD THAT FROM DORCAS HARDY STARTING FIRST THING YESTERDAY MORNING. I KNOW YOU ARE ENERGIZED FOR IT. IT'S FAIR TO SAY IT'S NOT EASY BUT DIFFICULT WORK. I AM GOING TO INTRODUCE STEVEN TINGUS, MY BOSS, ALSO FELLOW CALIFORNIAN, WHO WILL GIVE US OUR CHARGE FOR TODAY, AND HELP ADD A LITTLE MORE MOTIVATION TO OUR PURPOSES. HE IS, AS YOU KNOW, THE DIRECTOR OF THE NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH. THAT'S WITHIN THE OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES AT THE DEPARTMENT OF EDUCATION. HIS BIO IS IN YOUR PACKET. HE IS ALSO THE CHAIR OF THE INTER-AGENCY COMMITTEE ON DISABILITY RESEARCH, WHICH NOW HAS SIX SUBCOMMITTEES -- FIVE SUBCOMMITTEES. AS I SAID, HE IS A FELLOW CALIFORNIAN. BEFORE HE CAME TO NIDRR, JUST ABOUT FOUR YEARS AGO, HE WAS THE DIRECTOR OF RESOURCE DEVELOPMENT AND PUBLIC POLICY FOR ASSISTIVE TECHNOLOGY FOR THE CALIFORNIA FOUNDATION FOR INDEPENDENT LIVING CENTERS. HE ALSO GOT HIS MASTER'S DEGREE AND DID ADDITIONAL GRAD WORK AT U. C. DAVIS. PLEASE JOIN ME IN WELCOMING STEVEN TINGUS.

(APPLAUSE)

STEVEN TINGUS: GOOD MORNING, EVERYBODY. ALL RIGHT, STRETCH.

#### (LAUGHTER)

STEVEN TINGUS: IT'S GOING TO BE A VERY BUSY DAY, I WILL MAKE SURE OF THAT, ALONG WITH MARGARET. I AM HONORED AND PLEASED TO BE A PART OF THIS UNPRECEDENTED MEETING OF LEADERS IN THE DISABILITY AND AGING COMMUNITIES. WE ARE HERE AND WE ARE A PART OF HISTORY TODAY. A PART OF HISTORY WHEN IT COMES TO ISSUES AND OPPORTUNITIES FOR POLICY DEVELOPMENT, WHEN THE INTERSECTION OF DISABILITY AND AGING ARE GREAT. PEOPLE ARE LIVING LONGER, THOSE WITH DISABILITIES FOR INSTANCE, THAT HAVE LONG-TERM DISABILITIES ARE AGING WITH DISABILITIES, OUR CITIZENS WANT TO REMAIN HEALTHY, ACTIVE, PRODUCTIVE AND INVOLVED IN SOCIETY. OUR CHALLENGE HERE TODAY IS TO RECOMMEND SPECIFIC POLICY CHANGES, SERVICES SUPPORTS, TECHNOLOGIES AND RESEARCH THAT WILL HELP US ACHIEVE OUR SHARED GOALS. YESTERDAY WE HEARD A INFORMATIVE AND INSPIRING TALK BY A NUMBER OF OUTSTANDING LEADERS AND FEATURED

SPEAKERS. I MUST COMMEND DORCAS HARDING, ANDY, GENE SPERLING, KAREN IGNAGNI AND (INAUDIBLE), WHO SENT A GREAT MESSAGE FROM AHIP TO THE DISABILITY AND AGING COMMUNITY THAT I HAVE HEARD HERE, HER COMMITMENT TO OUR SHARED GOALS. CLAUDE ALLEN, OUTSTANDING LEADER FOR US IN BOTH AGING AND DISABILITY. JOHN HAGER, WHO IS VERY INVOLVED IN THE ACCOUNTABILITY AND THE IMPROVED OUTCOMES FOR PEOPLE WITH DISABILITIES, BOTH IN EMPLOYMENT AND INDEPENDENT LIVING. A SHARED GOAL HOMESTEAD IS FOR BOTH OF US NOT DISABILITY NOT AGING BUT - I'M SORRY, BUT FOR OUR COMMUNITY. GILBERT DEVEY FROM NSF. GREG. AND ALSO, IMPORTANTLY,

THE WORK OF THE PLANNING COMMITTEE HEADED BY WINTHROP, FROM AHIP, AND MY FRIEND MARGARET CAMPBELL, WHO HAS A LONG HISTORY OF BRINGING THE TWO COMMUNITIES TOGETHER.

AS I REFLECT ON OUR ACTIVITIES, I WOULD LIKE TO OFFER SOME REMARKS FROM A RESEARCH AND CONSUMER PERSPECTIVE. AS MARGARET SAID, WHEN I COORDINATED THE LONG-TERM CARE PROGRAM IN CALIFORNIA, I MADE IT KNOWN TO THE LEADERSHIP HOW IMPORTANT IT WAS FOR THE DISABILITY COMMUNITY TO WORK WITH THE AAA AT THE LOCAL LEVEL TO ENFORCE AND IMPROVE POLICIES WITH REGARD TO CONSOLIDATION OF RESOURCES. ALSO, WITH REGARD TO IMPROVING THE ACCESS FOR PEOPLE WITH DISABILITIES AND THOSE WITH A DISABILITY WITH REGARD TO TECHNOLOGY. IF IT WEREN'T FOR TECHNOLOGY, AND ALSO FOR PERSONAL ASSISTANT SERVICES, I WOULD NOT BE HERE TO DEFEND THE NEEDS OF OUR COMMUNITY. SYSTEMS TECHNOLOGY, A.T., AND WORKPLACE SUPPORTS ARE PIVOTAL TO OUR PRODUCTIVITY. TODAY IN THE ROOM WE HAVE A NUMBER OF NIDRR FUNDED CENTERS ON EMPLOYMENT, ON IO MANAGEMENT, ON TECHNOLOGIES FOR SUCCESSFUL AGING.

WE RUN THE GAMUT ON DISABILITY. AND WE ARE PROUD TO FURTHER THIS RESEARCH PHASE SO THAT INFORMS YOU IN MAKING YOUR DECISIONS TODAY. AS MARGARET HAS SAID THAT OUR WORK IS NOT DONE. THERE IS A NEXUS BETWEEN THE DISABILITY AND THE AGING COMMUNITY. WE ARE AT A POINT WHERE WE, IN THIS ROOM, CAN HELP DESTROY THE SILOS YET RESPECT OUR INDIVIDUALS GOALS AND OUR SHARED GOAL FOR IMPROVING THE PROMISES FOR PRODUCTIVITY AND HEALTHY LIVING FOR THE 21ST CENTURY. TODAY YOU WILL BE BUILDING ON YOUR EXPERTISE TO HELP US DEVELOP RECOMMENDATIONS TO THE WHITE HOUSE CONFERENCE ON AGING IN DECEMBER. IT'S AN IMPORTANT TASK THAT WE VALUE YOUR COMMITMENT. SO, AS WE BREAK UP THIS MORNING, I WANT TO URGE YOU TO PULL BACK YOUR SLEEVES, THINK OUT OF THE BOX, AND DEVELOP SOME CONCRETE POLICY RECOMMENDATIONS THAT WILL BENEFIT US ALL. I WANT TO THANK YOU. AND ON BEHALF OF WINTHROP, MARGARET AND THE PLANNING COMMITTEE, WE WANT TO THANK YOU FOR YOUR ACTIVE INVOLVEMENT. THANK YOU.

#### (APPLAUSE)

WINTHROP CASHDOLLAR: THANK YOU VERY MUCH, STEVE. MARGARET AND I AND THE PLANNING COMMITTEE APPRECIATE YOUR REMARKS. BRIEFLY LET ME ANSWER A FEW FREQUENTLY ASKED QUESTIONS AND THEN TALK ABOUT WHERE WE GO FROM HERE. THE FREQUENTLY ASKED QUESTIONS HAVE BEEN ABOUT SUCH THINGS AS THE PRESENTATIONS, THE POWERPOINT PRESENTATIONS THAT WE HAVE, ATTENDEE LISTS AND SO FORTH, WE ARE PLANNING AND WORKING TO PROVIDE BY POSTING ON THE WEBSITE ELECTRONICALLY OR OTHER MEANS AS MANY POWERPOINT PRESENTATIONS AS HAVE BEEN PRESENTED HERE AS WE GET PERMISSION FOR. WE ARE TRYING TO ARRANGE TO POST THEM ON THE WHITE HOUSE CONFERENCE ON AGING WEBSITE, WHICH IS WWW.WHCOA.GOV. THEY ARE NOT THERE NOW. WE HAVE OUR OWN LITTLE SPOT ON THE WEBSITE, YOU CAN FIND IF YOU CLICK ON MINI CONFERENCES, AND GO TO THE CALENDAR WHERE YOUR EVENT IS THE ATTENDEE LIST WE ARE GOING IT POST IT SO THE PEOPLE CAN HAVE THAT. AND AS PEOPLE HAVE ALSO MENTIONED, THERE WILL BE A REPORT COMING OUT OF THIS -- THESE PROCEEDINGS THAT WE WILL MAKE AVAILABLE TO YOU, THE PARTICIPANTS IN IT. A WORD ABOUT THE REPORT. WE HAVE TRIED TO EMPHASIZE THE FACT THAT WE REALLY CAN ONLY MAKE A LIMITED NUMBER OF TOP RECOMMENDATIONS TO THE WHITE HOUSE CONFERENCE ON AGING POLICY COMMITTEE, BUT THE PLANNING GROUP AND THE PEOPLE WHO WILL OFFER THAT REPORT WANT TO MAKE IT CLEAR TO EVERYONE HERE THAT, YES, WE WILL FEATURE A VERY LIMITED NUMBER OF RECOMMENDATIONS, BUT WE ALSO WANT TO CAPTURE THE FLAVOR OF THE WORK OF ALL OF THE SEPARATE POLICY DEVELOPMENT SESSIONS, INCLUDE THAT IN A REPORT THAT CAN BE A ROAD MAP THAT CAN HELP WITH SOME OF THE IMPLEMENTATION AND SOLUTION WORK THAT'S GOING TO COME AFTER THIS CONFERENCE.

SO, IF YOU ARE WORRIED ABOUT THE LIMITATION OF, SAY, NEEDING TO WORK ON ONE SINGLE RECOMMENDATION IN YOUR CONCURRENT BREAK-OUT SESSION, DON'T WORRY ABOUT THAT, WE WILL CAPTURE WHAT WE NEED TO BE OF USE TO THE POLICY COMMITTEE AND TO ALL OF THE PEOPLE WHO ARE INVOLVED IN IMPLEMENTATION ACTIVITIES. THANK YOU FOR COMING BACK AGAIN TODAY. WE ARE AT THE POINT, AS MARGARET AND STEVE MADE CLEAR, WHERE THE RUBBER MEETS THE ROAD. BRIEFLY BEING IN THE TRAFFIC COP ROLE I AM PLAYING, WE ARE GOING TO BREAK INTO THE FIVE CONCURRENT POLICY GROUPS. I YOU THINK YOU KNOW WHO YOU ARE AND WHERE YOU NEED TO GO. SO WE CAN HIT THE GROUND RUNNING. WE ARE GOING TO WORK AWAY UNTIL ABOUT NOON. I WANT YOU TO KNOW, ALTHOUGH WE HAVEN'T PLANNED A BREAK, THERE WILL BE REFRESHMENT, COFFEE AND BEVERAGES OUT HERE AROUND 10:30. AT ABOUT NOON, WE WILL PROVIDE LUNCH. LUNCH IS SCHEDULED FOR 12:15, AND WHAT'S GOING TO HAPPEN OVER THAT PERIOD IS YOU ALL, FOR THE MOST PART, CAN TAKE A WELL-EARNED BREAK AND JUST EAT AND MINGLE AS YOU WILL, AND A FEW PEOPLE WHO HAVE ASSIGNED ROLLS WITH THE CONCURRENT POLICY DEVELOPMENT SESSIONS WILL HUDDLE AND TRY TO WORK ON A PRESENTATION THAT CAPTURES THE WORK OF EACH OF THE GROUPS, THAT WILL BE ESSENTIALLY THE

SUBSTANTIVE CONCLUSION OF OUR WORK. SO, LUNCH IS SCHEDULED TO GO TO ABOUT 1:15, AND THEN AT 1:30 WE HAVE A CLOSING SESSION AT WHICH THE CONCURRENT POLICY GROUPS ARE GOING TO REPORT BACK TO YOU. AND THEN WE WILL CONCLUDE WITH DORCAS HARDY'S REMARKS. AGAIN, THANK YOU, AND GOOD LUCK.

(LAUGHTER) (APPLAUSE)

(END OF OPENING REMARKS)

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CRYSTAL CITY MARRIOTT,

MINI-CONFERENCE OF THE

2005 WHITE HOUSE CONFERENCE ON AGING

JULY 22, 2005

(CLOSING SESSION)

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JENNIFER SHEEHY KELLER: GOOD AFTERNOON, EVERYBODY. THANK YOU FOR JOINING US AGAIN.

WE ARE GOING TO START OUR -- OUR CLOSING SESSION AND THIS SHOULD BE VERY, VERY EXCITING AND THE CULMINATION OF A DAY AND A HALF OF EXTREMELY HARD WORK, SO THANK YOU VERY MUCH. AND FOR THE SAKE OF TIME I AM GOING TO MOVE RIGHT IN. MIKE DELAND COULDN'T JOIN US TODAY BUT THE NATIONAL ORGANIZATION ON DISABILITY IS ABLY REPRESENTED BY A GOOD FRIEND, NANCY STARNS. I WILL GIVE YOU A COUPLE OF POINTS ABOUT NANCY BECAUSE SHE HAS THE LONGEST LIST OF ACTIVITIES AND ON A RESUME THAT I HAVE EVER SEEN. SHE IS NOW THE VICE-PRESIDENT AND CHIEF OF STAFF OF THE NATIONAL ORGANIZATION ON DISABILITY. AND ONE OF THE THINGS SHE IS RESPONSIBLE FOR THAT MOST OF YOU KNOW ABOUT IS THE ACCESSIBLE AMERICA CONTEST. THE GREAT THING ABOUT THIS CONTENT, A LOT OF ORGANIZATIONS HAS TAKEN IT ON AS A MODEL, AND THAT'S GOOD FOR ALL OF US. SHE ALSO WAS -- SHE IS NOW THE FIRST VICE-PRESIDENT OF THE BOARD OF THE INDEPENDENT CENTER OF NORTHERN VIRGINIA. SHE IS A FORMER MAYOR OF SPARTA, NEW JERSEY. SHE WAS THE DIRECTOR OF TWO COUNTY OFFICES OF PEOPLE WITH DISABILITIES. SHE STARTED THE EAST COAST ADAPTIVE ALLIANCE. I THINK MOST IMPORTANTLY SHE PLAYED THE DOPRO IN A BLUE GRASS BAND FOR TEN YEARS. SO WE COULD ENCOURAGE HER TO PERFORM FOR US MAYBE. PLEASE JOIN ME IN WELCOMING NANCY.

#### (APPLAUSE.)

NANCY STARNS: THANK YOU VERY MUCH JENNIFER, AND THANK YOU ALL FOR ALLOWING ME TO CRASH YOUR PARTY TODAY. I CRASH WEDDINGS AND OTHER THINGS TOO. I KNOW MICHAEL DELAND SENDS HIS REGARDS AND THE FOUNDER OF NOD. I, MYSELF, WITH A PERSON WITH A WHEEL IN EACH OF THE AREAS YOU ARE TALKING ABOUT, BOTH DISABILITY AND AGING, THIS CONFERENCE IS PARTICULARLY INTERESTING TO ME AND MANY, MANY PEOPLE ACROSS THE COUNTRY WHO ARE EITHER AGING WITH DISABILITY OR AGING INTO DISABILITY. THE NATIONAL ORGANIZATION ON DISABILITY IS -- HAS BEEN AROUND MORE THAN 23 YEARS FOUNDED AS AN OUT GROWTH OF THE DISABLED PERSONS, IT'S A U.N. INITIATIVE THAT NOD FOUNDER ALLEN REICH HEADED UP. WE NEEDED TO GO BEYOND A SINGLE YEAR AND MAKE IT A FULL-TIME MISSION OF HIS AND NOD'S.

WE ARE PROUD THAT WE HAVE GOT PROGRAMS THAT HAVE GROWN UP TO ADDRESS THE ISSUES OF AMERICA'S 54 MILLION MEN, WOMEN AND CHILDREN WITH DISABILITIES ACROSS THIS COUNTRY. WE DO ADDRESS ALL ISSUES FOR THOSE INDIVIDUALS. WE ARE PROUD TO HAVE COMMUNITY PARTNERSHIP PROGRAM WORKING WITH US, WE HAVE WORKED WITH 4,000 MAYORS ACROSS THE COUNTRY SINCE 1982. WE HAVE A NATIONAL PARTNERSHIP PROGRAM SUPPORTING THE LARGEST ASSOCIATIONS AND ORGANIZATIONS IN THIS COUNTRY THAT ARE NOT DISABLED RELATED AND THEY DO INCLUDE AARP. WE HAVE STARTED A SUCCESS PROGRAM, MENTORING PROGRAM FOR YOUTH WITH DISABILITIES. I KNOW YOU HEARD FROM MY COLLEGE GINNY ABOUT THAT PROGRAM YESTERDAY, AND OUR NEWEST IS THE EMERGENCY PREPAREDNESS INITIATIVE FOR PEOPLE WITH DISABILITIES. THIS IS AN ISSUE THAT'S GOING TO BE GROWING IN IMPORTANCE FOR NOT ONLY PEOPLE WITH DISABILITIES AND PEOPLE WHO ARE AGING, BUT EVERYBODY IN THE COUNTRY IS GOING TO BE INVOLVED IN IT. THIS IS A BOOKLET THAT WAS REPORTED THE FIRST EVER CONFERENCE HELD ON THIS TOPIC IN 2004. SO WE ARE PROUD TO BE A VAST REPOSITORY FOR THAT KIND OF INFORMATION. WE ALSO HAVE INTERNATIONAL -- WHICH DOESN'T

PRESENT AN AWARD EACH YEAR, TO THE COUNTRY THAT BEST EXEMPLIFIES THE U.N. PROGRAMS INITIATIVES FOR PEOPLE WITH DISABILITIES. WE LOVE DOING EVERY FOUR YEARS A SURVEY THAT DOCUMENTS THE PARTICIPATION GAPS THAT EXIST BETWEEN WITH AND WITHOUT DISABILITIES, SO WE ARE JUST -- WE COULDN'T BE HAPPIER THAN TO BE ABLE TO ADD TO THE KIND OF WORK THAT YOU ALL ARE DOING THAT WE THINK IS GOING TO BE IMPORTANT TO THIS COUNTRY, NOT ONLY THOSE OF US IN THE CATEGORY BUT ALL OF THE SONS AND DAUGHTERS, SISTERS AND BROTHERS AND OTHER PEOPLE THAT CARE SO MUCH ABOUT US. JUST SO YOU HAVE AN UNDERSTANDING OF HOW THIS SESSION IS GOING TO GO, WE ARE STARTING JUST A WEE BIT LATE.

WE ARE GOING TO GIVE EVERYBODY APPROXIMATELY SIX MINUTES EACH TO PRESENT THEIR RESOLUTIONS. DON'T WORRY IF YOU DON'T GET AN OPPORTUNITY TO GET YOUR QUESTION AND ANSWERS IN AFTER EVERYBODY HAS THE RESOLUTIONS UP BECAUSE THERE WILL BE PLENTY OF OPPORTUNITY FOR YOU TO WEIGH IN WITH CONCERNS, YOUR COMMENTS, QUESTIONS BEFORE THE FINAL REPORT IS ISSUED.

WITH THAT, I WANT YOU TO KNOW WE ARE GOING TO GO IN ORDER OF THE NUMBERED SESSIONS, THE FIRST PRESENTER FOR SOCIAL ENGAGEMENT AND PRODUCTIVITY IS KEN MITCHELL.

KEN: I WOULD LIKE TO GIVE THANKS TO OUR PARTICIPANTS. WHO ACTED LIKE ADULTS AND WERE ABLE TO DO A LOT OF BODY CHECKING IN A VERY NICE AND PASSIONATE WAY. OUR GROUP REALLY OFFERED A GREAT DEAL OF ENJOYMENT AND FUN. WE THANK YOU FOR THAT. I WOULD LIKE TO THANK SUSAN DANIELS AND CAROL WHO ARE -- LED US IN A VERY SIGNIFICANT EFFORT. AS YOU KNOW, SUSAN IS A RENAISSANCE WOMAN WHO WAS ABLE TO TURN OUR PROGRAM INTO A FUNDRAISER.

(LAUGHTER).

KEN: DO YOU WANT TO SAY SOMETHING REAL QUICKLY?

SUSAN: SURE. ANDY COME ON OVER. I TRY TO DO A FUNDRAISER AS WELL, TODAY WE RAISED FUNDS FOR THE AMERICAN ASSOCIATION FOR PEOPLE WITH DISABILITIES, ANYONE IN OUR ROOM, ANY A WOMAN -- MEN TOO -- ANY WOMAN WITH PANTY HOSE ON HAD TO PAY A DOLLAR. ALL MEN WHO WORE TIES TO THE SESSION NOT BUSINESS CASUAL ALSO HAD TO PAY A DOLLAR. WE COLLECTED I THINK 7 OR 8 DOLLARS. LUCY IS CARRYING THEM IN HER POCKET.

(APPLAUSE)

(LAUGHTER).

KEN: WE HAVE TWO PEOPLE THAT CAME BY AND SAW THE DOG HAD THE MONEY IN THE POUCH, WHY DOES THE DOG CARRY LOOSE CHANGE? OUR GROUP WAS ABLE TO TAKE 16 RECOMMENDATIONS THAT WERE OFFERED. WE DID AGREE SOCIAL ENGAGEMENT AND PRODUCTIVITY ARE CONNECTED. WE SAW THAT OUR RESOLUTIONS AND RECOMMENDATIONS COVERED THE SPAN FROM WORK, INDEPENDENT LIVING AND TO SOCIAL AUTONOMY. WE WERE ABLE TO GLEAN OUT OF THE 16 THREE BASIC RESOLUTIONS. ONE IS WE WANTED TO HAVE IMPACT, ENACT LEGISLATION TO PROVIDE INCENTIVE. WE WANTED TO ESTABLISH A COHERENT RESEARCH AGENDA BASED ON THE IDEA DISABILITIES ARE COMPLEX, CONFOUNDING AND COMPETING. WE WANTED TO PROMOTE FUNDING FOR MASS TRANSIT TO ASSURE COMMUNITIES WERE CONNECTED FOR SOCIAL AND PRODUCTIVITY AREAS. SO, WHAT WE WANTED TO DO IS MAKE WHAT WE FELT WAS OUR PRIMARY RESOLUTION AND PRIMARY RECOMMENDATION, THAT IS CONGRESS SHOULD ENACT LEGISLATION TO PROVIDE BARRIERS SO EMPLOYEES CAN HIRE AND RETAIN OLDER WORKERS WITH AND WITHOUT DISABILITIES. THE BARRIERS THAT NEED TO BE SPECIFIC, NEED TO BE FOCUSED, AND WE WILL BE ABLE TO ESTABLISH THE VEHICLE BY WHICH THIS RESOLUTION WILL GO FORWARD. WE THINK THIS VEHICLE HAS TO BE IN A PUBLIC-PRIVATE TYPE OF PARTNERSHIP, THIS IS NOT A GOVERNMENT ISSUE OR PRIVATE ISSUE, AND THE ONLY WAY IT'S GOING TO BE SOLVED IS THROUGH PUBLIC AND PRIVATE PARTNERSHIP. WE THINK THE BEST WAY TO CLOSE OUR RESOLUTION IS CITE A WISE GENTLEMAN. THAT'S GEORGE BURNS.HE HAD IT JUST ABOUT RIGHT WHEN HE SAID, "I CAN'T GET OLD, I AM WORKING." AS LONG AS YOU ARE WORKING, YOU STAY YOUNG. THANKS A LOT.

(APPLAUSE)

NANCY: SESSION NUMBER 2, HEALTHY LONG-TERM LIVING.

}} HI. JUST A FEW WORDS ABOUT THE PROCESS. IN OUR GROUP WE DIDN'T RAISE ANY MONEY, UNFORTUNATELY WE HAD FOUR RECOMMENDATIONS THAT WE ALL DIVIDED INTO SUBGROUPS TO DISCUSS FURTHER OR I SHOULD SAY BROAD AREAS FROM WHICH RECOMMENDATIONS COULD BE CRAFTED. AND WE -- I STARTED WITH THE GROUP ON HOME AND COMMUNITY SERVICES AND SUPPORTS. AND WE -- WE HAD A DECISION TO TRY TO CRAFT EITHER A BROAD STATEMENT OR A MORE SPECIFIC STATEMENT. THE OPTIONS BEING A BROAD STATEMENT MIGHT BE ABLE TO -- TO INDICATE WHERE THE

PROBLEM AREAS ARE, BUT THE SPECIFIC THINGS MIGHT BE THINGS THAT ARE MORE LIKELY TO BE ACTED ON. SO, WE DEVELOPED THIS -- WE DECIDED TO DEVELOP A BROADER SCALE RECOMMENDATION THAT WE HOPE SOME OF THE OTHER RECOMMENDATIONS COULD BE INCORPORATED WITHIN.SO LET ME JUST READ THIS TO YOU. CONGRESS SHOULD ENACT LEGISLATION TO PROVIDE INCENTIVES -- OOPS. I'M SORRY. THIS ONE. I THOUGHT -- THAT WAS CONGRESS.

#### (LAUGHTER).

}} THE NATION SHALL ADOPT AND FULLY FUND A SYSTEM THAT WILL ASSURE THAT PEOPLE WITH DISABILITIES ACROSS THE LIFE SPAN CAN CHOOSE FROM A FULL RANGE OF CULTURAL AND LINGUISTICALLY APPROPRIATE CONSUMER DIRECTED -- AND WE FELT ALSO DISABILITY APPROPRIATE CONSUMER DIRECTED HOME AND COMMUNITY SERVICES AND SUPPORTS THAT ARE NOT INSTITUTIONALLY BIASED AND THAT MEET INDIVIDUALS NEEDS. THIS SYSTEM WOULD INCLUDE AND BE

SUPPORTED BY PUBLIC AND PRIVATE FUNDING FOR COMPREHENSIVE COORDINATED TIMELY SCREENING, EVALUATION AND SERVICES DESIGNED TO PREVENT DECLINE AND IMPROVE FUNCTIONAL CAPACITY TAILORED TO STAGE -- TO AGE, SEX, DISABILITIES CHRONIC HEALTH CONDITIONS AND PERSONAL LIFESTYLE HISTORY. A CONGRESSIONAL MANDATE ON FUNDING OF A COORDINATED INTER-DISCIPLINARY HEALTH RESEARCH AGENDA ON AGING WITH A DISABILITY, WHETHER THAT'S COGNITIVE, PHYSICAL, SENSORY, BEHAVIORAL OR SOME COMBINATION OF THESE DISABILITIES, SHOULD BE UNDERTAKEN ACROSS ALL RELEVANT FEDERAL AGENCIES. WE HAD IN MIND OF COURSE CDC, NIH, PARTICULARLY THE NATIONAL INSTITUTE ON AGING, AND TO ADDRESS THE ISSUE OF THERE BEING LITTLE RESEARCH ON THIS TOPIC AS THE -- AS THE PRESS RELEASE IN YOUR HANDOUT NOTED. ALSO, THAT THERE IS A NEED FOR COMPETENT DISABILITY SPECIFIC EDUCATION AND TRAINING FOR PAID PROVIDERS OF SERVICES AND SUPPORTS, TO ENSURE APPROPRIATE ACCESS TO INFORMATION AND TRAINING AS WELL FOR INFORMAL CARE PROVIDERS. SO, THAT COVER AS LOT OF TERRITORY. WE WERE ABLE TO, I THINK, INCORPORATE THE MAJOR CONCERNS OF THE FOLLOWING PEOPLE IN OUR GROUP. IF SOMEONE OBJECTS TO THAT PLEASE SAY SO. WHY IS THIS NEEDED? WELL, I THINK WE ALL KNOW WHY IT'S NEEDED. MANY PEOPLE WITH DISABILITIES SIMPLY DON'T HAVE THE ACCESS TO THE HEALTH CARE THAT WE ALL TAKE FOR GRANTED.

FOR EXAMPLE, PREVENTIVE SCREENING FOR CANCER. WE FELT THAT NEEDED TO BE ADDRESSED. FURTHER, LONG-TERM SERVICES AND SUPPORTS ARE NOT SUFFICIENT FOR MILLIONS OF AMERICANS WITH DISABILITIES AND THIS INCLUDES MANY PEOPLE DRIVEN BY FORCES OUT OF THEIR CONTROL INTO INSTITUTIONS AGAINST THEIR WILL OFTEN AND THE INSTITUTIONAL BIAS MENTIONED MANY TIMES IN THIS CONFERENCE ALREADY.

## WE NEEDED TO ADDRESS THAT.

AND IN ADDITION, WE KNOW THERE ARE MILLIONS OF PEOPLE LIVING IN A COMMUNITY WHO HAVE UNMET NEEDS THAT INCREASE THEIR ADVERSE CONSEQUENCES SUCH AS FALLS, AND OTHER INJURIES, AND ALSO CAUSE INADEOUATE NUTRITION BECAUSE I CAN'T GET THE FOOD THEY NEED OR PREPARE IT THE RIGHT WAY. THAT LEADS TO UNINTENTIONAL WEIGHT LOSS, DEHYDRATION AND INCREASE RISK OF STROKE TO NAME A FEW. THESE ARE ALL ADVERSE CONSEQUENCES THAT ARE COSTLY TO US. AND THAT EXPAND THE COST OF ACUTE HEALTH CARE BUT THEY ARE AVOIDABLE AND THEY NEED TO BE ADDRESSED. THE OBSTACLES TO THIS ARE ESSENTIALLY COST EVERYBODY AGREES IN PRINCIPLE WITH THE IDEAS HERE, AND WE HAVEN'T GIVEN ENOUGH ATTENTION TO THE COSTS AND BENEFITS OF THESE PROPOSALS. ALTERNATIVE PROPOSALS THAT EXIST. OVER THE SHORT-TERM THERE ARE A NUMBER OF PROPOSALS THAT ARE OUT THERE THAT NEED TO BE ACTED UPON. THAT INCLUDES MONEY FOLLOWS THE PERSON, MICASSA THAT'S BEEN BEFORE CONGRESS 8 YEARS, LOTS OF PEOPLE SUPPORT IT, NOBODY WANTS TO VOTE ON IT BECAUSE THE CBO SAYS IT COSTS 10 TO 20 BILLION DOLLARS TO IMPLEMENT. WE HAVE SOME RESEARCH THAT WE HAVE BEEN WORKING ON THAT INDICATES IT WOULD BE FAR LESS THAN THAT. SO WE NEED TO HAVE THAT DIALOGUE. AND THE LONGER TERM WE NEED TO INTEGRATE MEDICARE MEDICAID FINANCING LONG-TERM SERVICES AND SUPPORTS PERHAPS BY CREATING A PARTY TO BENEFIT FOR EXAMPLE. AND WE NEED RESEARCH. TO UNDERSTAND THESE ISSUES ABOUT ACCESS AND HOW PEOPLE WITH DISABILITIES ARE AGING. ACCESS TO LONG-TERM SERVICES AND SUPPORTS. THIS IS CRITICALLY IMPORTANT WE NEED TO BUILD BETTER DATA SYSTEMS FOR EXAMPLE THE NATIONAL LONG-TERM CARE IS SURVEY THE ONLY NATIONAL POPULATION BASED LONG-TERM CARE SURVEY IN THIS COUNTRY ARE ONLY FOR PEOPLE 55 YEARS OF AGE AND OLDER YET WE KNOW HALF THE PEOPLE THAT NEED LONG-TERM CARE IS 18 TO 64.

WE NEED TO SOLVE THESE PROBLEMS. WHO WOULD DO THAT? CERTAINLY CONGRESS AND THE ADMINISTRATION NEED TO WORK ON THE PROPOSALS THAT EXIST NOW THAT ARE BEFORE CONGRESS AND AT THEM MICASSA NEEDS TO BE GIVEN A HEARING PARTICULARLY ON THE COST AND BENEFITS OF MICASSA AND PROCEED TO A VOTE. 8 YEARS BEFORE CONGRESS IS TOO LONG A TIME TO BE STAYING BEFORE CONGRESS. CONGRESS AND THE ADMINISTRATION NEED TO ADVANCE NEW PROPOSALS FOR

SYSTEMS CHANGE AND REAL CHOICE OPTIONS THAT WORK FOR PEOPLE WITH DISABILITIES. PERHAPS THE INTERAGENCY COMMITTEE FOR DISABILITY RESEARCH CAN GET OTHER AGENCIES TO COORDINATE ACTIVITIES AROUND THE RESEARCH THAT'S NEEDED ON AGING WITH A DISABILITY. AND HOW CAN WE EVALUATE THIS? WELL, IT WOULD BE NICE TO GET A FEW PIECES OF LEGISLATION ENACTED INTO LAW, I THINK THAT'S AN OBJECTIVE MEASURE. AND I THINK WE JUST NEED TO ADVANCE SOME NEW PROPOSALS THAT ARE REALLY GOING TO ADDRESS THE ISSUES THAT ARE RAISED HERE TODAY. THANKS.

(APPLAUSE)

NANCY: THANKS VERY MUCH, MITCH. A LOT OF PEOPLE WHO ARE, YOU KNOW, ON THIS AGING PATH, HAVE TO WORRY ABOUT THEIR ECONOMIC SECURITY SESSION, 3 DEALT WITH ECONOMIC SECURITY PLANNING AND CHOICE. JILL AND MR. DAVIS ARE GOING TO PRESENT THE RESOLUTIONS FOR THIS TOPIC.

}} GOOD AFTERNOON. I KIND OF FEEL LIKE GENE SPERLING YESTERDAY TALKING ABOUT HITTING THE BUTTON, I WANT IT TO GO THIS WAY INSTEAD OF THIS WAY (INDICATING). I NEED TO RAISE THE MICROPHONE. OUR GROUP FOCUSED ON THREE POINTS TO BEGIN WITH NUMBER ONE, WE BEGAN THE PROCESS BY REVIEWING TWO POLICY PAPERS THAT WAS A COMPILATION OF THE RECOMMENDATIONS THAT WERE PUT FORTH TO OUR COMMITTEE. WE CAME TO CONSENSUS, NUMBER TWO, THAT WHAT WE NEEDED TO DO WAS WE NEEDED TO CRAFT A VISION THAT WE COULD ALL FEEL COMFORTABLE WITH, AND THAT WE WOULD THEN COME OUT WITH FOUR TALKING POINTS THAT WERE REPRESENTATIVE OF THE DIRECTION THAT WE SEE THINGS HEADING. THE THIRD POINT WAS THAT WE RECOGNIZED THE FACT THAT THERE IS A LOT OF WORK TO BE DONE. WE HAD LIKE TWO PAGES FULL OF LIKE ALL OF THESE ISSUES THAT GOT US INTO THE WEEDS, WHEN WE GOT THERE WE GOT AWAY FROM WHERE WE HAD CONSENSUS. WE MADE A COMMITMENT AS A GROUP WHAT WE ARE GOING TO DO WAS COME TO CONSENSUS AND SHARE WITH YOU OUR FOUR POINTS OF COMMON GROUND AND YOUR VISION. AND THEN COMMIT TO WORKING TOGETHER AS A TEAM TO COMPLETING THE POLICY RECOMMENDATIONS AND WORK WITH WITH THAT SAID, OUR VISION IS THIS, IN THE CONTEXT OF A RAPIDLY MATURING SOCIETY FACED WITH AN ECONOMY THAT IS EVOLVING FROM AN AGRICULTURAL/MANUFACTURING BASE TO A 21ST CENTURY GLOBAL KNOWLEDGE SERVICE-BASED ECONOMY, WE WANT TO PRESERVE THE ECONOMIC SECURITY OF ALL AMERICANS ACROSS THE LIFE SPAN. AS SUCH, WE WANT TO ENCOURAGE A LIFELONG DEVELOPMENT OF TRANSFERABLE SKILLS, SLASH, INCENTIVES THAT WILL ENABLE ALL AMERICANS TO PARTICIPATE IN THE ECONOMY ACCORDING TO THE EXTENT OF THEIR ABILITIES AND CHOICES WITH APPROPRIATE SUPPORTS AND ACCOMMODATIONS. HOW IS THAT FOR SOME SERIOUSLY LONG SENTENCES? BUT THIS IS SOMETHING WE CAME TO CONSENSUS ON AND INCORPORATED THE GROUP'S THOUGHTS. MOVING ALONG, THE FOUR POINTS OF COMMON GROUND THAT WE CAME UP WITH ARE, NUMBER ONE, WE ALL FELT THAT IT IS IMPORTANT TO PRESERVE AND ENRICH PROTECTION OF THE OVERALL SOLVENCY OF THE SOCIAL SECURITY INSURANCE RETIREMENT AND DISABILITY SURVIVOR PROGRAMS. NUMBER TWO, REFORM EXISTING PUBLIC AND PRIVATE INCOME SUPPORTS AND PUBLIC AND PRIVATE LONG-TERM SERVICE AND SUPPORT PROGRAMS SUCH THAT THEY DO, A, INCORPORATE INCENTIVES AND REMOVE DISINCENTIVES TO SAVE, TO EARN, TO LEARN, TO PARTICIPATE IN COMMUNITY LIFE, AND PLAN. THAT'S -- ACTUALLY THAT SHOULD BE PARTICIPATE IN COMMUNITY LIFE AND PLAN IS ALL ONE BULLET, THAT'S NOT A SEPARATE BULLET LIKE IT SAYS PLAN. AND THEN B WOULD BE, TO IMPROVE THE STANDARD OF LIVING FOR PEOPLE WITH DISABILITIES ACROSS THE LIFE SPAN.

NOW, WHAT YOU WILL FIND WITH THESE TWO AREAS OF COMMON GROUND IS THAT, YOU KNOW, OBVIOUSLY THAT THERE IS A THEME THERE, IT'S ABOUT -- IT'S ABOUT SAFEGUARDING AND IMPROVING THE EXISTING PROGRAMS THAT WE HAVE. NOW, AS WE MOVE INTO -- OOPS. BACKWARDS. HOW DO I GO BACK? SORRY. TECHNICAL DIFFICULTY. THERE WE GO. NUMBER 3 TALKS ABOUT CREATING A NEW PUBLIC PRIVATE HYBRID WITH EARLY INTERVENTION ORIENTATION TO SUPPORT PEOPLE WHO CHOOSE TO REMAIN IN THE WORKFORCE AS THEY AGE AND AS THEY EXPERIENCE IMPAIRMENTS ASSOCIATED WITH DISABILITIES AND AGING. WE REALLY BELIEVE THAT IF THIS IS DONE RIGHT, THAT IF WE DO THIS RIGHT WE CAN CREATE A SAVINGS AND THAT IT WILL REALLY CREATE AN OPPORTUNITY FOR PEOPLE WHO CHOOSE TO WORK. AND NUMBER FOUR IS ABOUT ESTABLISHING A PAYROLL DEDUCTION THROUGHOUT THE PERSON'S WORK LIFE THAT WILL ENABLE THE INDIVIDUAL TO ACCESS LONG-TERM CARE WHEN NEEDED. THE THEME THAT YOU REALLY SEE HERE IS ABOUT ENCOURAGING PEOPLE TO PLAN FOR THE ONSET OF DISABILITY. TO PLAN FOR THE ONSET OF DISABILITY FROM THE MOMENT THAT THEY START WORKING, WITH THAT SAID, I WANT TO INVITE SPEED TO TAG TEAM HERE AND ELABORATE.

- }} ON WHAT?
- }} ON ANY OF THE --

(LAUGHTER).

}} ON ANY OF THE FOUR AREAS OF COMMON GROUND THAT OUR TEAM CAME UP.

- }} I THINK OUR BASIC CONCEPT, GOING BACK TO THE VISION, IS THAT WE NEED TO HAVE POLICIES AND PROGRAMS IN PLACE THAT WILL SUPPORT A PERSON'S CHANGING NEEDS, THEY NEED TO BE FLEXIBLE. WE KNOW AND HEARD A LOT YESTERDAY, AS WE AGE OUR INTERESTS OUR SKILLS OUR FUNCTION LEVELS ALL CHANGE. WE WERE LOOKING FOR DEVELOPING A SYSTEM THAT WOULD SUPPORT THAT INDIVIDUAL THROUGH THOSE CHANGES. IT MAY BE THAT THEY HAVE TO GET OUT OF THE WORKFORCE FOR A WHILE, IT MAY BE THAT THEY WANT IT GET BACK IN, IT MAY BE THAT THEY CAN USE SOME EARLY INTERVENTION.
- SOCIAL SECURITY IS BEGINNING TO LOOK AT THIS FOR REASONABLE ACCOMMODATIONS AND INTERVENTION THAT WOULD ALLOW THEM TO STAY IN THE WORKFORCE INSTEAD OF GOING OUT AND COME BACK IN. SO, THAT WAS YOUR OVERALL CONCEPT. WE HAD -- I THINK IF YOU LOOK AT THE PROPOSALS, THEY FALL INTO TWO AREAS, FIRST IS DO NO HARM. THERE WAS A STRONG SENTIMENT IN THE GROUP, THERE ARE A LOT OF PEOPLE, SOME WHO ARE DISABLED THAT THEY MAY NOT BE ABLE TO BE EMPLOYED. PROGRAMS THAT ARE SERVING THE NEEDS AT SOME LEVEL, NOW WE DON'T WANT TO TAKE THAT OUT FROM UNDER THEM. SO THAT'S WHY WE TALK ABOUT PRESERVING AND PROTECTING THE EXISTING PROGRAMS. WE WANT TO LOOK AT RAISING THE BENEFIT LEVELS SO THAT THEY PROVIDE SOMETHING OTHER THAN POVERTY LEVEL OF EXISTENCE AND THEN MAYBE PEG THOSE TO AN INDEX SO THEY CONTINUE TO GROW WITH THE PERSON'S COST OF LIVING. THE REST OF THE RECOMMENDATIONS WILL REALLY OPEN THE DOOR TO THE POSSIBILITY OF INNOVATION, TO REVAMP PERSONS IN THE WORKFORCE WHO WANT TO GET INTO THE WORKFORCE AT A LATER STAGE OF LIFE, TO BE ABLE TO ACCESS THROUGH ONE DOOR SIMILAR WHAT WE ARE DOING IN LABOR WITH ONE-STOP CAREER CENTERS GOING INTO ONE DOOR, BE ABLE TO GET THE CASH ASSISTANCE THE HEALTH CARE, THE HOUSING, THE TRANSPORTATION, THE ACCOMMODATIONS THAT THEY NEED TO BE -- TO MEET WHATEVER THEIR GOALS ARE FOR THEIR EMPLOYMENT, RETIREMENT AND TRANSITION BETWEEN THE VARIOUS THINGS.
- }} OUR GROUP REALLY FELT IT IS IMPORTANT AS WE WORK TO FURTHER REFINE OUR POLICY RECOMMENDATIONS THERE WERE THINGS LIKE, FOR EXAMPLE, RAISING THE FEDERAL BENEFIT RATE, FOLKS FELT STRONGLY IT NEEDED TO BE EXPLICITLY STATED. THERE WAS ALSO A GENERAL CONSENSUS WE NEEDED TO ENSURE WHATEVER WE ARE PUTTING FORTH RECOGNIZES THAT CHOICE -- THE CONCEPT OF CHOICE, AND ALSO IS ALL ENCOMPASSING OF ALL PEOPLE WITH DISABILITIES. SO, BEING VERY CROSS-DISABILITY CENTERED.
- }} CHOICE AND PLANNING WERE TWO PRIMARY PRINCIPLES, THE PERSON CHOOSING WHERE THEY WANT TO WORK CONTINUE TO WORK, ET CETERA. THE SERVICES THEY WANT TO ACCESS. BUT ALSO IN THE LAST ONE WHERE WE ARE TALKING ABOUT MAYBE A VOLUNTARY DEDUCTION FROM THEIR WAGES, THEY WORK THROUGHOUT THE LIFE CYCLE TO PUT THE BURDEN ON THEM, THE RESPONSIBILITY ON THE INDIVIDUAL TO START THINKING ABOUT AND PLANNING FOR THEIR LATER YEARS WHEN THEY MAY NEED FOR LONG-TERM SERVICES AT ONE POINT OR ANOTHER, SO WE ARE TRYING TO SHARE THAT BURDEN.
- }} THANK YOU.

## (APPLAUSE)

- }} NANCY: PEOPLE WITH DISABILITIES HAVE BECOME MORE AND MORE, ESPECIALLY FROM THE ONSET OF DISABILITY, TO RELY ON ALL SORTS OF ASSISTIVE TECHNOLOGY. THE NEXT SESSION IS GOING TO BE PRESENTED BY CELIA (INAUDIBLE). HOW CLOSE WAS THAT? NO CIGAR? TO TALK ABOUT THAT PARTICULAR ITEM.
- }} CELIA: THANK YOU, IT'S A PLEASURE TO BE ABLE TO REPRESENT THE GROUP THAT GOT TOGETHER YESTERDAY AFTERNOON AND THIS MORNING. I CAN'T NAME THEM ALL, BUT I REALLY APPRECIATE THEIR EFFORTS TO WORK TOGETHER TO COME UP WITH SOME RECOMMENDATIONS TODAY. WHEN I WENT INTO THIS JOB I WAS WORRIED ABOUT TWO THINGS, I WAS WORRIED THAT, NUMBER ONE, I WOULD COME UP THERE AND ASK FOR PEOPLE TO THROW OUT IDEAS AND DISCUSS THINGS AND THERE WOULD BE A BIG SILENCE AND I WOULD BE LEFT UP THERE WITH NOTHING TO PRESENT AT THE END OF THE SESSION. OR, ALTERNATIVELY, I WAS WORRIED WE WOULD HAVE PEOPLE TACKLING EACH OTHER, ARGUING AND MAKING IT VERY DIFFICULT TO COME TO SOME KIND OF CONSENSUS. I AM GLAD TO SAY NEITHER ONE OF THOSE THINGS HAPPENED. WE WERE ABLE TO COME UP WITH A LARGE NUMBER OF RECOMMENDATIONS TO DISCUSS THEM AND TO VOTE. AND I WILL TALK ABOUT THE ONES THAT WE IN A DEMOCRATIC PROCESS DECIDED WERE OUR MOST HIGHLY RECOMMENDED RECOMMENDATIONS. THEY ARE ALL SOMEWHAT EMBRYONIC, I THINK, SO I WILL BE WORKING WITH MARGARET CAMPBELL, OUR COORDINATOR, AND BOB YAEGER AND OTHERS IN THE GROUP TO FINALIZE THEM I WOULD LIKE TO SHARE WITH YOU THOSE. LISTENING TO THE OTHER PRESENTERS, THERE IS OBVIOUSLY A LOT OF CONNECTION AMONG ALL OF THESE CONCURRENT SESSIONS. I THINK THERE ARE OPPORTUNITIES FOR THE ORGANIZERS TO FIND THE LINKS AND COME UP WITH REALLY STRONG RECOMMENDATIONS OUT OF THIS MINI CONFERENCE.

OUR GOAL THEN WAS TO REALIZE THE POLICY GOALS OF UNIVERSAL DESIGN AND FULL ACCESS TO ASSISTIVE TECHNOLOGY -- AND ACCESSIBLE TECHNOLOGY, TO MAXIMIZE INDEPENDENCE CHOICE AND COMMUNITY LIVING FOR INDIVIDUALS WITH DISABILITIES AND OLDER ADULTS I THINK THERE IS MISSING "AND" THERE BY THESE FOLLOWING RECOMMENDATIONS. THE FIRST ONE PRETTY MUCH GOT THE LARGEST NUMBER OF VOTES FAR AND AWAY. I HAVE BOILED IT DOWN HERE TO RECAP WHAT WE TALKED ABOUT. WE DECIDED TO GO WITH A CARROT TO ESTABLISH A TAX CREDIT FEDERAL TAX CREDIT WHICH WOULD GIVE CREDIT TO THOSE WHO WERE MAKING HOMES MORE ACCESSIBLE OR VISIBLE. WE FELT THAT WE WOULD FOCUS ON THE HOME THAT THIS -- I SPECIFICALLY LEAVE OUT HERE WHO WILL GET THE TAX CREDIT THAT'S SOMEWHAT NEEDS TO BE CRAFTED CAREFULLY. PEOPLE WHO RENT SHOULD BE ABLE TO TAKE ADVANTAGE OF THIS SOMEHOW, THOSE WHO HAVE HOMES WHO AREN'T DISABLED BUT ARE TO BE VISITED BY THOSE WHO ARE OR BY OLDER FAMILY MEMBERS FOR EXAMPLE SHOULD BE INCENTIVEIZED TO MAKE THEIR HOMES ACCESSIBLE. THAT WAS OUR NUMBER ONE RECOMMENDATION.

THE NEXT ONE IS TO EXPAND THE USE OF FEDERAL PROCUREMENT INCENTIVES TO PROMOTE AVAILABILITY AND UTILIZATION OF ACCESSIBLE UNIVERSALLY DESIGNED TECHNOLOGIES. THIS IS ESSENTIALLY AN EXPANSION OF SOMETHING LIKE THE SECTION 508 POLICIES OR STATUTE, TO USE THE FEDERAL PROCUREMENT SYSTEM TO ENCOURAGE MANUFACTURERS AND THOSE WHO MAKE GOODS AND SERVICES MORE ACCESSIBLE TO OLDER AMERICANS AND PEOPLE WITH DISABILITIES. THE THIRD RECOMMENDATION -- AND THESE -- THESE LAST THREE ARE NOT IN ANY PARTICULAR ORDER, ALTHOUGH, THE FIRST ONE WAS OUR PRIMARY ONE, THE THIRD ONE IS TO AMEND THE OLDER AMERICAN'S ACT TO MANDATE THE DEVELOPMENT AND DELIVERY OF TRANSGENERATIONAL ASSISTIVE AND ACCESSIBLE UNIVERSALLY DESIGNED TECHNOLOGIES AND ENVIRONMENTAL INTERVENTIONS. WE TRIED TO CAPTURE BROAD TECHNOLOGIES NOT JUST USE THE TERM ASSISTIVE TECHNOLOGY BUT TO BE BROADER. THIS RECOMMENDATION GOES TO THE ISSUE WHICH WAS RAISED THAT THE OLDER AMERICANS ACT, ON THE ONE HAND, DOES NOT MAKE PROVISIONS FOR PROVIDING ASSISTIVE TECHNOLOGY TO OLDER AMERICANS ON THE OTHER HAND THE ACT DOES NOT ADDRESS ISSUES SPECIFIC TO AGE RELATED DISABILITY WE FELT THERE MIGHT BE A NEED TO ADDRESS THE GAP BETWEEN THESE TWO PIECES OF LEGISLATION. OUR FOURTH AND FINAL POLICY RECOMMENDATION WAS ONE WHICH

WE FELT WAS VERY IMPORTANT, BUT WE WEREN'T SURE WHAT THE FEDERAL ROLE NECESSARILY SHOULD BE. I THINK IT'S AN IDEA THAT BASED ON MEMBERS OF THE GROUP HAVE BEEN RAISED BEFORE, BUT HAS NEVER BEEN ENACTED. AND SO TO THE EXTENT THAT THE FEDERAL GOVERNMENT CAN PLAY A ROLE, WE FELT THAT THERE NEEDED TO BE A NATIONAL CONSUMERS UNION TO PROVIDE INFORMATION ABOUT ASSISTIVE TECHNOLOGY. ESSENTIALLY SOMETHING LIKE CONSUMERS REPORTS TO DO BOTH CUSTOMER SURVEYS AND PERHAPS HAVE SOME SENIOR SEAL OF APPROVAL TO INDICATE WHICH TECHNOLOGIES PRODUCTS AND SERVICES REALLY WERE USEFUL, AND TO ALSO DO SOME KIND OF TESTING AND RATINGS SIMILAR TO THE CONSUMER REPORTS ANNUAL ISSUE ON CARS THERE MIGHT BE AN ANNUAL ISSUE ON ASSISTIVE TECHNOLOGY. SO, THOSE WERE THE FOUR RECOMMENDATIONS THAT WE ARE BRINGING FORWARD TO YOU, AND HOPEFULLY WE WILL BE ABLE TO PROVIDE ADDITIONAL INFORMATION FOR THE FINAL REPORT. THANK YOU.

## (APPLAUSE)

- }} NANCY: THANK YOU VERY MUCH. IT'S ALWAYS DIFFICULT TO SELL A NEW IDEA OR NEW PROGRAM WITHOUT A MARKETING PIECE TO IT. THIS IS SESSION NUMBER 5, IT'S ABOUT POSITIVE MESSAGING.AND SHEILA IS GOING TO BE PRESENTER FOR THE FINAL SESSION.
- }} SHEILA: WE HAD A LIVELY DEBATE ABOUT POSITIVE MESSAGING LOOKING AT SOME OF THE ISSUES THAT ARE LIMITING IN TERMS OF PEOPLE'S PERCEPTIONS AROUND INDIVIDUALS WHO ARE AGING OR INDIVIDUALS WITH DISABILITIES AND THE IMPORTANCE OF THE MESSAGE NEEDING TO BE ACROSS THE SPECTRUM OF INDIVIDUALS AND OUR RECOMMENDATIONS REALLY ORIENT TOWARD ALL AMERICANS, AND BEING ALL REFLECTIVE, RATHER THAN LOOKING AT INDIVIDUAL GROUPS. IN THAT PROCESS TO IDENTIFY THE -- OUR PLANNING PROCESS OUR FIRST STEP WAS REALLY TO LOOK AT WHAT OUR GOAL WAS WHAT WAS THE VISION THAT WAS DRIVING THE MESSAGE THAT NEEDED TO BE COMMUNICATED. AND THE VISION STATEMENT THAT WE CAME UP WITH IS COMMUNITIES WHERE THROUGH PURPOSEFUL AND TARGETED MESSAGING EVERYONE LIVES AND PARTICIPATES FULLY IN ACCORDANCE WITH INDIVIDUAL CHOICE AND DIRECTION, FREE OF LABELING AND STEREOTYPICAL EXPECTATIONS ABOUT LIFE QUALITIES. KIND OF A DEFINING CHARACTERISTICS WE WERE THINKING ABOUT IN TERMS OF POLICY RECOMMENDATIONS. I WANT TO ADD IN TERMS OF OUR GROUP PROCESS WE HAD REACHED CONSENSUS ON ALL OF THESE ISSUES BUT THEN WORKED SOME OF THE LANGUAGE THROUGH AFTER THE SESSION MUCH OF IT BEING WRITTEN OUT AS WE WERE WALKING IN THE ROOM. SO THERE IS GOING TO BE AN OPPORTUNITY FOR AMONG OUR GROUP MEMBERS TO REVIEW THE LANGUAGE AS WELL BEFORE WE MOVE THE FULL RECOMMENDATION FORWARD. RELATIVE TO OUR POLICY RECOMMENDATION, WE WOULD RECOMMEND THAT THE PRESIDENT ISSUE AN EXECUTIVE ORDER REQUIRING GOVERNMENT AGENCIES TO

EVALUATE THEIR POLICIES AND DEVELOP A COMPREHENSIVE PLAN WHICH OUTLINES GOALS AND MEASURABLE OBJECTIVES TO PROMOTE LIVEABLE COMMUNITIES SUPPORTING THE NEEDS OF ALL AMERICANS THROUGHOUT THE LIFE SPAN. WELL, THAT WAS ACTUALLY SOME OF THE PEOPLE FROM THE COMMITTEE, I THINK WE MANAGED TO CAPTURE IT. I WASN'T SURE WE ARE GOING TO GET CLAPPING OR BOOING, APPARENTLY WE DID OKAY. AS A MECHANISM TOO AS PART OF THE PROCESS EACH GOVERNMENT AGENCY WILL NEED TO DELIVER THEIR PLAN TO THE PRESIDENT ON OR BEFORE JULY 26TH 2008, SUCH PLANS WILL ADDRESS AND STRENGTHEN POLICIES RELATED TO ECONOMIC SECURITY PLANNING AND CHOICE, SOCIAL ENGAGEMENT AND PRODUCTIVITY, HEALTHY LONG-TERM LIVING, TECHNOLOGY UNIVERSAL DESIGN AND ENVIRONMENTS AND POSITIVE MESSAGING. YOU MAY SEE A LITTLE BIT OF A CONSISTENCY IN THE LANGUAGE THERE. THOSE ARE THE CRITICAL VARIABLES THAT NEED TO BE CONSIDERED IN THINKING ABOUT THIS WHOLE MESSAGING PROCESS. AND SOME THOUGHTS ABOUT WHAT THE PLAN WILL ADDRESS POLICIES THAT INCLUDE, BUT WOULD NOT NECESSARILY BE LIMITED TO, PRIVATE AND PUBLIC PARTNERSHIPS, PUBLIC SOLICITATION FOR GRANTS CONTRACTS AND COOPERATIVE AGREEMENTS. PARTICULARLY IN THINKING ABOUT THIS FROM A MESSAGING PERSPECTIVE THE LANGUAGE USED IN TALKING ABOUT DIFFERENT KINDS OF SERVICES OR SUPPORTS WOULD BE A CRITICAL VARIABLE IN THAT. MEDIA OUTREACH AND PUBLIC INFORMATION CAMPAIGNS. BOTH INTER AND INTRA GOVERNMENT ACCOUNTABILITY MECHANISMS SUCH AS THE GPRA, PART AND CAM. WE REALIZED THERE WAS ONLY 3 LETTERS WE GOT IN THERE FROM THE ALPHABET. THE RULES GUIDING PUBLIC PROCUREMENT REFERENCE TO PERSONAL AGENCY AND OTHER FORMS OF SELF DIRECTION AND LEADING TO INDIVIDUAL CHOICE AND CONTROL. AND PARTICIPATION IN A COORDINATED MEDIA CAMPAIGN, DEVELOPED IN CONJUNCTION WITH REPRESENTATIVES OF THE DISABILITY AND AGING COMMUNITIES AND EXPERTS IN STRATEGIC COMMUNICATION.

#### (APPLAUSE)

}} NANCY: SO MANY OF THE THINGS THAT EVERYBODY IS TALKING ABOUT REALLY ALL OF THESE HAPPEN AGAINST THE BACK DROP OF COMMUNITIES, THAT'S KIND OF A NICE SETTING TO TALK ABOUT HOW YOU DELIVER AND MAKE THE CHANGES AT THE POINT WHERE THE RUBBER DOES MEET THE ROAD. IT'S YOUR TURN TO ASK QUESTIONS OF YOUR REPRESENTATIVES OF THESE FIVE GROUPS, AND YOU WILL HAVE APPROXIMATELY 25 MINUTES TO DO THAT. SEE HOW HAPPY THEY ARE ALL, LOOK AT SMILING FACES.

# }} MITCH?

- }} WE HAVE MICROPHONES AND HANDHELDS WE WILL BRING AROUND TO PEOPLE IN THE AUDIENCE IF ANYONE HAS QUESTIONS.
- }} I JUST WANTED TO COMMEND, THE ECONOMIC PRODUCTIVITY GROUP FOR FOCUSING TO SOME EXTENT ON EARLY INTERVENTION AND KEEPING PEOPLE AT WORK. BECAUSE I THINK THAT IN THE EXPERIENCE OF SOCIAL SECURITY AND TRYING TO GET PEOPLE WHO ARE ALREADY ON THE ROLLS BACK TO WORK THE TICKET TO WORK CERTAINLY HAS FALLEN SHORT OF OUR EXPECTATIONS, AND ANYTHING THAT WE CAN DO TO HELP PEOPLE AVOID THIS PROCESS OF HAVING TO APPLY FOR SOCIAL SECURITY AND GET ON THE ROLLS IN THE FIRST PLACE IS MONEY AND TIME WELL SPENT.
- }} THANK YOU, THAT WAS A VERY IMPORTANT PRINCIPLE IN OUR DISCUSSION EASILY RECOGNIZED, IT'S EASIER TO KEEP THE PERSON ON THE JOB PRODUCTIVE IN THE EYES OF THE EMPLOYER THAN TO HAVE THEM GO AWAY AND COME BACK AND REESTABLISH THAT CREDIBILITY SO THANK YOU.
- }} AS THE EXECUTIVE DIRECTOR OF THE TICKET TO WORK AND WORK INCENTIVE ADVISORY PANEL, I WOULD BE REMISS TO NOT SHARE WITH YOU THAT IT'S EXCITING TO BE WITH SUCH A CROSS-SECTION OF STAKEHOLDERS HERE, AND WE CONTINUE TO TALK ABOUT THIS PIECE OF LEGISLATION. WE ARE IN A PERIOD OF PLANNING, LAYING OUT OUR STRATEGIC PLAN FOR THE NEXT TWO YEARS. AND I AM -- I CAN SPEAK ON BEHALF OF THE PANEL, THEY WOULD BE VERY INTERESTED IN HEARING FROM YOU AS STAKEHOLDERS IN ISSUES THAT -- THAT YOU SEE AS PRIORITIES, BECAUSE WE HAVE A LIMITED AMOUNT OF TIME. WE HAVE UNTIL DECEMBER 17TH 2007 ON BEHALF OF THE CHAIR AND MEMBERS OF THE PANEL WE WOULD REALLY WELCOME YOUR INPUT AS STAKEHOLDERS ON WHAT WE SHOULD BE FOCUSING ON, AND HOW WE CAN WORK ON IT TOGETHER.
- }} THANK YOU, THERE IS A HAND IN THE BACK. OH, GOOD. THIS IS REALLY FOR YOU ALL TO COMMENT.
- }} DOUG, ARE YOU IN THE ROOM? ARE YOU GONE? WE WERE TALKING THIS MORNING ABOUT A SIMILAR IDEA ABOUT KEEPING PEOPLE IN COMMUNITY, THAT ONCE THEY ARE -- PEOPLE ARE AT RISK OF GOING INTO INSTITUTIONS, AND SO THERE SHOULD BE A WAY TO HAVE KIND OF LIKE A -- A WAY TO PREVENT PEOPLE FROM GOING INTO INSTITUTIONS, THE SAME WAY OF KEEPING PEOPLE ON THE JOB. SO IF YOU NEED THE MECHANISMS FOR FINDING AT RISK PEOPLE WHO ARE AT RISK OF BEING INSTITUTIONALIZED I

THINK THAT PIGGYBACKS THE EMPLOYMENT IDEA OF KEEPING PEOPLE ON THE JOB. IT'S CHEAPER TO KEEP PEOPLE AT HOME RATHER THAN TO PULL THEM OUT, TRY TO PUT THEM BACK IN THE COMMUNITY FOLLOWING BEING INSTITUTIONALIZED.

- }} THANK YOU. OTHER COMMENTS OR QUESTIONS? RANTS OR RAVES?
- }} IF I COULD RESPOND TO THAT QUICKLY, THE LAST COMMENTS THE CONCEPT OF KEEPING PEOPLE OUT OF INSTITUTIONS AND ON THE JOB, I THINK ULTIMATELY WE TRY TO GET THIS I THINK IN THE THIRD OR FOURTH RECOMMENDATIONS WE ARE TALKING ABOUT RESPONDING TO GENE'S COMMENTS ABOUT THE NEW PARADIGM AND TALKING ABOUT RESPONDING TO (INAUDIBLE). WE NEED TO STAND BACK, AND WE DID ACTUALLY IN OUR GROUP TALK BRIEFLY ABOUT SOME SORT OF A BLUE RIBBON PANEL, THAT WOULD STAND BACK AND TAKE A RETHINKING OF THE ISSUES AROUND THAT WE HAVE BEEN TALKING ABOUT HERE WITH THE POSSIBILITY OF COMPLETELY REDESIGNING, RESTRUCTURING, ET CETERA, THE PROGRAMS, POLICIES AND SERVICES THAT SUPPORT THE THINKING WE HAVE BEEN TALKING ABOUT HERE.
- }} SPEED, YOU WOKE THEM UP OUT THERE, I SEE TWO HANDS. GENTLEMAN IN THE FRONT AND THEN WE WILL GET TO YOU IN THE BACK.
- }} GOOD AFTERNOON, THIS IS MILFORD FROM THE NATIONAL COUNCIL OF DISABILITY. I HAVE A SENSE AN URGENCY, BECAUSE AS I HAVE EXPERIENCED PERSONALLY AND I HAVE LEARNED THROUGH MY INVOLVEMENT AS A MEMBER OF THE NATIONAL COUNCIL ON DISABILITY AND AS AN ATTORNEY REPRESENTING THE GOVERNMENT, IN MANY INSTANCES DEALING WITH MATTERS THAT HAVE TO DO WITH DISABILITY AS A CIVIL RIGHTS ATTORNEY, I SEE THAT IF WE CAN AT LEAST BRING TO THE WHITE HOUSE CONFERENCE ON AGING SOMETHING CONCRETE ABOUT EMPLOYMENT. EMPLOYMENT IS SOMETHING THAT CUTS ACROSS ALL OF THE FACETS OF LIFE FOR PEOPLE WITH DISABILITY AND PERSONS THAT ARE AGING. EMPLOYMENT IS SIGNIFICANT .AND NECESSARY SUPPORT SYSTEM TO ASSIST THOSE PEOPLE THAT ARE EITHER DISABLED OR ARE AGING THAT MAY END UP WITH SOME DISABILITY DOWN THE ROAD. IF I CAN -- IF I SEE MY -- PERSONALLY AS A CITIZEN OF THIS NATION, AS A PART OF THE DISABILITY COMMUNITY, SEE THAT WE BRING A SUCCESSFUL RECOMMENDATION THAT WILL BE IMPLEMENTED DOWN THE ROAD HAVING TO DO WITH EMPLOYMENT THAT WOULD BE FANTASTIC. THAT'S THE ONLY THING I WANTED TO SAY. WE HAVE EXPERIENCED THAT IN OUR PERSONAL LIFE AND WE SEE IN MANY, MANY PEOPLE THAT WE KNOW IN THE PROCESS EMPLOYMENT IS KEY. AND PUBLICLY SUPPORTED SERVICES AND SOME SORT OF A -- SOME SORT OF A CARE SYSTEM FOR THEM. THANK YOU.

# }} THANK YOU.AND IN THE BACK?

- }} I AM SALLY, EXECUTIVE DIRECTOR OF THE COMMITTEE FOR PEOPLE WITH INTELLECTUAL DISABILITIES. I WANT TO FOLLOW UP ON MILTON'S RECOMMENDATIONS ON THE WORK INCENTIVES AND TAKING THOSE RESTRICTIONS OFF THOSE BARRIERS, TO GO EVEN FURTHER AND HELP PRONOUNCE A QUALIFIED SAVINGS ACCOUNT OR HAVING PEOPLE THAT RECEIVE BENEFITS AS A PART OF THE INDIVIDUAL DEVELOPMENT OF ACCOUNTS LIKE WE DO IN OUR AGENCY. IN THE WASHINGTON POST THIS MORNING THERE WAS AN ARTICLE ON PEOPLE WITH GETTING BENEFITS FOR SAVINGS, WELL PEOPLE WITH DISABILITIES, ESPECIALLY INTELLECTUAL DISABILITIES, NEED THE OPPORTUNITY TO SAVE AND SAVE IN YOUTH SO THEY CAN HAVE AN OPPORTUNITY IN AGING WHERE THEY HAVE AN ACCOUNT, WHERE THEY CAN FIND THOSE -- THOSE FACILITIES OR THOSE -- I AM TRYING TO THINK OF THE WORD, MAYBE -- VEHICLES TO USE HOW THEY WANT TO USE THEIR MONEY. SAVINGS IS A PART OF THE AMERICAN DREAM. THANK YOU.
- }} AS PART OF OUR DISCUSSION, WE RECOGNIZED THE SAVINGS PROGRAMS THAT EXIST LIKE INDIVIDUAL DEVELOPING ACCOUNTS HAVE THEIR OWN RESTRICTIVE RULES THAT THE PROGRAMS LIKE SOCIAL SECURITY AND SSI THE PEOPLE ARE ENROLLED IN RIGHT NOW HAVE THEIR OWN RULES AND ALL MITIGATE AGAINST THAT KIND OF A THING. WE DID RECOGNIZE THE NEED, AND I TALKED ABOUT THE TAKING OUT ALL OF THOSE UNNECESSARY RESTRICTIONS TO FREE UP PEOPLE WITH DISABILITIES AND BE ABLE TO DO THE KINDS OF SAVINGS AND PLANNING THAT PEOPLE WITHOUT DISABILITIES ARE ABLE TO DO FROM YOUTH.

## }} RIGHT ON. THANK YOU.

}} THANK YOU, MA'AM. I WANTED TO RAISE AN ISSUE THAT MADE IT TO NUMBER 5 IN OUR GROUP OF 4. AND JUST TO SUGGEST THAT THERE MIGHT BE INTEREST ON -- AMONG OTHER MEMBER GROUPS ON THIS. WE FEEL THERE IS FUNDAMENTAL CIVIL RIGHTS ISSUE ABOUT ACCESS TO THE INTERNET ESPECIALLY AS THE ISSUE OF ACCESS BECOMES MORE AND MORE IMPORTANT TO THE SERVICE DELIVERY OF SENIORS OR OLDER AMERICANS OR PEOPLE WITH DISABILITIES FOR LEARNING AND LIFELONG LEARNING FOR COMMERCE, THE ABILITY TO BUY, SHOP, AND ALSO FOR THE ISSUE OF COMMUNITY, DISABILITY COMMUNITY. FOR US TO BE ABLE TO TALK AND SHARE WITH EACH OTHER, TO LEARN FROM EACH OTHER, ABOUT OUR CONDITIONS, WHAT SPECIFIC TECHNOLOGIES WORK AND DON'T WORK FOR US. SO, I AM JUST PUTTING IN A PITCH AND SUGGESTING WHEN WE STRIP IT ALL OUT THERE SHOULD BE A CLARIFICATION

ON POLICY ABOUT THE RIGHT OF ALL OF US TO -- CIVIL RIGHT, TO HAVE ACCESS TO THE INTERNET, WHICH DOESN'T PRESENTLY EXIST TODAY.

- }} VERY GOOD. YES?
- }} THANK YOU. I JUST WANTED TO -- I JUST WANTED TO COMMEND SESSION 2, HEALTHY LONG-TERM LIVING FOR THE LONG ENDORSEMENT OF RESEARCH AGENDA ON AGING WITH DISABILITY. I KNOW MITCH MENTIONED FROM THE PODIUM, I WANTED TO CALL YOUR ATTENTION TO IT AGAIN, ONE OF THE THINGS WE TALK ABOUT WHEN WE TALK ABOUT IT FAIRLY LOOSELY PEOPLE WITH LONG-TERM DISABILITIES WHETHER THEY ARE IN THEIR 20'S, 30'S, 40'S, 50'S SO ON ARE AT GREATER RISK FOR SECONDARY CONDITIONS. THIS IS FRONT AND CENTER IN THE HEALTHY PEOPLE 2010 REPORT CHAPTER 6, UP UNTIL VERY RECENTLY WE HAD NO POPULATION BASED DATA ON WHAT THE PREVALENCE OF SECONDARY CONDITIONS ARE AMONG PEOPLE WITH LONG-TERM LIVING WITH -- LIVING WITH LONG-TERM DISABILITIES. SO WE INCLUDED IN YOUR FACT SHEET, I DON'T KNOW HOW MUCH TIME -- HOW MANY HAVE TIME TO SEE THE FIRST STUDY THAT I WAS TALKING WITH MITCH ABOUT IT IS INDEED THE VERY FIRST STUDY USING POPULATION BASED DATA AND COMES UP WITH ESTIMATES OF THIS PREVALENCE THE RESULTS ARE INCLUDED IN OUR FACT SHEET. IT REALLY IS A MAJOR AND VERY SIGNIFICANT PROBLEM WHICH UNDERMINES EMPLOYMENT THE COMMUNITY LIVING, ET CETERA. YOU KNOW WHAT THE LONG-TERM CONSEQUENCE OF SECONDARY CONDITIONS IS? PREMATURE DEATH SO THIS IS A VERY, VERY SERIOUS PROBLEM, AND I AM DELIGHTED TO SEE IT FRONT AND CENTER IN YOUR RECOMMENDATIONS, THANK YOU.
- }} THANK YOU.
- }} ARE THERE MORE? YOU HAVEN'T USED UP YOUR ALLOTTED TIME. MY GOODNESS, HOW DO YOU EXPECT TO GET INTO POLITICS THIS WAY?
- }} I WANT TO ECHO MILTON'S REMARKS AND THIS LADY'S REMARK ABOUT ASSET DEVELOPMENT. I HAVE A CAUTION TO ALL OF THIS. THE ASSET DEVELOPMENT RULES AND SSI AND THE MICASSA RULES WHICH WOULD AMEND MEDICAID WE ARE HITCHING A GREAT DEAL OF OUR DREAMS TO POVERTY PROGRAMS. I AM NOT SAYING DOING AWAY WITH POVERTY PROGRAMS, I AM NOT SAYING TO DO HARM TO ANYONE, BUT IF WE ARE LOOKING FOR SUBSTANTIVE REFORM THAT ENDS UP WITH FULL INCLUSION, WHETHER THAT BE EMPLOYMENT OF CHOICE OR APARTMENT OF CHOICE AS A COMMUNITY, WE STILL SEEM TO BE HITCHING OUR DREAMS TO PROGRAMS THAT SAY GET MORE AND WE WILL GIVE YOU WHAT YOU NEED. SO, IT'S A LEVEL OF REFORM, IT'S A LEVEL OF COMMITMENT THAT WE WANT FULL INCLUSION THAT I WOULD PUT BEFORE YOU WE MAY NOT BE CLEAR YET ABOUT SUBSTANTIVE LEVEL OF REFORM IT WILL BE. SOCIAL INSURANCE DOESN'T CARE HOW MUCH MONEY YOU HAVE IN THE BANK, MEDICAID DOES, I AM NOT SAYING DO HARM, I AM NOT SAYING GET RID OF MEDICAID, SSI, THEY ARE DESPERATELY NEEDED PROGRAMS, BUT WE ARE HITCHING OUR DREAMS OF FULL INCLUSION TO PROGRAMS THAT WEREN'T BUILT TO DO THAT. AND I QUESTION HOW WE ARE TWEAKING PROGRAMS OR TRANSFORMING FEDERAL COMMITMENT TO GET TO FULL INCLUSION, WHETHER THAT WILL TAKE A LEVEL OF REFORM THAT CONTINUES TO TWEAK AT BACK DOORS THROUGH INNUMERABLE WAIVERS IN COMPLEXITY OR TRANSFORMING INSTITUTIONS TO A FUNDAMENTAL LEVEL OF FULL INCLUSION THAT I THINK MILTON AND MANY PEOPLE IN THIS ROOM WANT.
- }} THANK YOU. WE WILL COME BACK TO YOU IN A SECOND. THIS LADY BACK THERE, EVERYBODY SPEAKS ONCE MAYBE BEFORE WE GO BACK AND OVER THE SAME GROUP LIST AGAIN.
- }} SUE ELLEN, I THINK BRIAN, WE MAY BE TALKING ABOUT THE SAME THING. THE EMPHASIS IS DIFFERENT FROM THE GROUP WITH THE HEALTHY LONG-TERM LIFE WHATEVER, WE -- YOU WILL FIND WE NEVER MENTION THE WORDS MEDICAID OR MEDICARE. I THINK THAT'S WHAT IS HOLDING US IN CERTAIN BOXES. SO, THAT -- WE CAN BE HITCHING OUR STAR TO OLD BOXES, WHEN IT'S NOT REFERENCING, TALKING ABOUT WHAT IT IS THAT YOU NEED, AND THE FACT THAT, THANKFULLY, DR. GIANNINI, EILEEN AND OTHERS SAW FIT TO SEE THAT DISABILITY HAD A PLACE AT THE CONFERENCE ON AGING. I WISH THERE WAS A WHITE HOUSE CONFERENCE ON DISABILITIES IN THE PROPOSED 6 YEARS AGO BUT THAT'S WHERE SOME OF THE LANGUAGE BARRIERS, I THINK, COME FROM THAT AT LEAST DIVIDE THINGS UP AND INSTEAD OF GOING TOGETHER WHERE THERE IS COMMONALITY. THIS FORCING SOME OF THE SAME PROGRAMS OR FUNDING SOURCES IS JUST NOT THE WAY TO GO.
- }} ALL RIGHT, MILT, WOULD YOU LIKE -- YOU HAD ANOTHER RESPONSE?
- }} YES, SORRY. I COME BACK AGAIN, I WANT TO INDICATE THIS, UM, THERE ARE SEVERAL THINGS THAT I THINK THAT AT LEAST WE CAN HAVE AT LEAST ONE RECOMMENDATION GO TO THE CONGRESS, ONE HAVING TO DO WITH EMPLOYMENT, ONE HAVING TO DO WITH LONG-TERM CARE, ONE HAVING TO DO WITH TRANSPORTATION ISSUES RELATED TO PERSONS WITH DISABILITIES, AND ELDERLY, AND ONE THAT HAS TO DO WITH SUPPORT ASSISTANCE. LET'S SAY A PERSON WITH DISABILITIES NEEDS PEOPLE IN THE

COMMUNITIES WHO WILL ASSIST THEM IN EITHER MOVING TO THE JOB, GOING TO THE STORE TO BUY OR GOING TO THE THEATER, WHATEVER WE NEED A PERSONAL CARE ATTENDANT AND NEED A RECOMMENDATION FROM THE WHITE HOUSE REGARDING WHAT A WHOLE SET OF FACTORS THAT AFFECT THE ABILITY OF THAT PERSON IN THE COMMUNITY TO ASSIST THAT INDIVIDUAL WITH A DISABILITY OR WITH AGING. AND ALSO, THE CONCEPT OF SOME SORT OF SOCIAL INSURANCE PROGRAM THAT PEOPLE CAN CONTRIBUTE A LONGER LIFE SPAN, SO THAT WHEN -- THAT THEY PAY FOR -- THAT EVENTUALLY CAN BE USED TOGETHER WITH WHATEVER PROGRAM THE GOVERNMENT SUPPLYS. THERE ARE FIVE AREAS, AT LEAST ONE RECOMMENDATION INITIAL THOSE GROUPS GO TO THE WHITE HOUSE, WE HAVE COVERED MOST OF WHAT WE HAVE DISCUSSED HERE THAT'S WHAT I WANTED TO SAY, THANK YOU.

- }} OKAY. ANY OTHER QUESTIONS?
- }} I DON'T HAVE A QUESTION BUT ACTUALLY A RESPONSE -- I THINK IT'S A MAJOR MISTAKE TO SEND IN FIVE RECOMMENDATIONS ABOUT FIVE DIFFERENT THINGS. WE NEED RECOMMENDATIONS THAT ARE HOLISTIC AND COVER EVERYTHING BECAUSE THE FRAGMENTATION IS EXIST WHY WE HAVE THE SITUATION THAT WE HAVE TODAY. SOME THINGS BEING PAID OUT OF ONE AREA, OTHER THINGS BEING PAID OUT OF ANOTHER AND SOME THINGS NOT BEING PAID AT ALL.

(APPLAUSE)

- }} SO WE NEED TO THINK ABOUT HOW WE ARE GOING TO BRING TRANSPORTATION, HOW WE ARE GOING TO BRING HOUSING, HOW WE ARE GOING TO BRING UNIVERSAL DESIGN AND LONG-TERM CARE ALL INTO ONE HOLISTIC POLICY.
- }} ALWAYS A CHALLENGE HOW TO BUNDLE THE ISSUES SO YOU HAVE GREATEST IMPACT, AND IT'S MOST RELEVANT TO THE DIFFERENT GROUPS THAT WILL BE MEETING AT THE WHITE HOUSE CONFERENCE EXACTLY, HUGE CHALLENGE. OTHER COMMENTS OR QUESTIONS? AGAIN, YOU WILL HAVE AN OPPORTUNITY TO CONTINUE WEIGHING IN ON THE DOCUMENT AS IT'S REFINED AND EDITED AND DEVELOPED, WITH THAT I THINK YOU WANT TO EXPRESS YOUR APPRECIATION FOR THE WORK OF ALL OF THESE WORKING GROUPS, AND AGAIN TO THE PLANNERS FOR THIS FANTASTIC CONFERENCE, AND THEN YOU WILL HEAR FROM YOUR CLOSING SPEAKER.

(APPLAUSE)

}} RIGHT ON TIME MY GOODNESS.

(LAUGHTER).

}} WINTHROP CASHDOLLAR: ON TIME AT LAST. JUST A BRIEF MOMENT BEFORE DORCAS HARDY RETURNS TO THE PODIUM TO AMPLIFY WHAT NANCY AND OTHERS HAVE SAID THANKS TO ALL OF THE GREAT PEOPLE WHO STOOD UP HERE TRYING TO REPRESENT THE LAST THREE HOURS OF ORGANIZED CHAOS. AND THANKS TO THE PEOPLE WHO PUT IT IN SOME SEMBLANCE OF PRESENTABILITY, I REALLY APPRECIATE THAT. THIS IS A WORK IN PROGRESS, WE ARE -- OUR PLANNING COMMITTEE IS GOING TO GO BACK TO THE DRAWING BOARD AND ATTEMPT TO MAKE THE RECOMMENDATIONS, BUT ALSO CAPTURE THE CONTEXT THE VISION AND TO MR. SANFORD'S POINT TRY TO BREAK DOWN SOME OF THE WALLS BETWEEN THE SILOS AND GET TO THE LEVEL OF INTEGRATION AND BOLDNESS. WE ARE KEEPING ALL OF THE POST-IT NOTES, THE NAPKINS, THE BACKS OF THE ENVELOPES. WE ARE GOING TO USE THOSE AND -- AND I HAVE BEEN ASKED ALSO TO NOTE THAT PEOPLE WHO PARTICIPATED TODAY SHOULD FEEL ENCOURAGED TO HAVE FURTHER CONVERSATIONS, EITHER THROUGH ME OR DIRECTLY WITH THE PEOPLE WHO WERE TRYING TO RUN THE SESSIONS AND FACILITATE THEM SO WE CAN MAKE SURE WE HAVE THE BEST PRODUCT FOR DORCAS THAT WE CAN. WITH THAT, I WILL WELCOME DORCAS HARDY, CHAIRMAN OF THE

POLICY COMMITMENT OF THE WHITE HOUSE CONGRESS ON AGING BACK TO THE PODIUM. DORCAS?

(APPLAUSE)

}} DORCAS HARDY: GOOD AFTERNOON, AND THANK YOU, WINTHROP. THIS HAS BEEN AN AUGUST BODY. I DIDN'T GET BACK TO HEAR ALL OF THE PRESENTATIONS BUT I GOT QUITE OF A BIT OF AN UPDATE.AND I AM VERY IMPRESSED. I HAVE HIGH EXPECTATIONS, SO I AM NOT SURPRISED, BUT I AM VERY IMPRESSED. YOU SHOULD BE CONGRATULATED FOR ALL OF YOUR HARD WORK. ONCE AGAIN, THE PLANNERS GOT YOU FOCUSED AND DID A REALLY GOOD JOB. IT'S BEEN AN OUTSTANDING MINI CONFERENCE. I WOULD SAY IT'S ONE OF THE HIGHLIGHTS, IF I SAID IT IS THE HIGHLIGHT, THEN I GET IN TROUBLE WITH EVERYBODY ELSE, SO LET'S LEAVE IT THERE. YOU HAVE DONE A GREAT JOB. YOU HAVE REALLY SEEMED TO HAVE PULLED TOGETHER. I LISTENED TO A FEW OF THE REMARKS THAT WERE RECENTLY MADE, AND I JUST WOULD LIKE TO THANK ALL OF YOU, YOUR PARTNERS, THE STAFF, EVERYBODY WHO GOT TOGETHER TO DO THIS. THIS IS A TOUGH JOB. AND I EXPECT WHEN WE SEE THE RESOLUTIONS PUT TOGETHER, THE FINAL EFFORT THAT COMES FROM THE PLANNING STAFF, FROM ALL OF YOU WEIGHING IN SOME MORE,

THAT IT REALLY WILL BE OUTSTANDING. REMEMBER, IT'S THE ONLY WHITE HOUSE CONFERENCE ON AGING MINI CONFERENCE ON DISABILITY AND AGING, SO YOU GUYS REALLY GOT -- IT'S A STAR-STUDDED, AND I EXPECT THE FINAL RESOLUTIONS WILL BE AS WELL. IT'S CLEAR YOU PUT A LOT OF THOUGHT INTO ALL OF THIS AND I JUST WANTED TO LOOK AT SOME OF THE THINGS THAT I HEARD ABOUT AND, USE SOME OF THE COMMENTS ABOUT YESTERDAY WHICH I THOUGHT WAS VERY PROVOCATIVE AS WELL, LAYING THE GROUNDWORK, AGING WITH DISABILITIES, AGING TO DISABILITY, AND I THINK THOSE ARE TWO CONCEPTS THAT WE REALLY NEED TO KEEP IN THE BACK OF OUR MIND OR FOREFRONT OF OUR MINDS, ACTUALLY, AS WE ARE GOING THROUGH ALL OF THESE ISSUES. WE DO HAVE DIFFERENT TYPES OF FOLKS, WE HAVE A MAJOR WORKFORCE, WE HAVE A MAJOR GROUP OF PEOPLE COMING IN AND GOING OUT OF DISABILITIES.

SO, WE HAVE GOT TO BE LOOKING ACROSS THE BOARD. SEEMS TO ME WORK OPPORTUNITIES WAS A HIGHLIGHT, NOT ONLY FROM THE PRIVATE BUT ALSO THE PUBLIC SECTOR YESTERDAY. PUBLIC PRIVATE PARTNERSHIPS RELATED TO EVERYONE AND ESPECIALLY RELATED TO DISABILITY INSURANCE. I THINK THE WHOLE QUESTION OF INDEPENDENCE KEEPS COMING UP. ALL OF US WANT, I THINK, TO CONTINUE A VERY SERIOUS CONVERSATION ABOUT IN THE PRESERVATION OF INDEPENDENCE FOR INDIVIDUALS. UM, PROBABLY ADDRESSING THE HOUSING ARENA THE CAREGIVER FIELD USE OF TECHNOLOGY THE SUPPORT SERVICES THAT WAS JUST TALKED ABOUT HERE. THE WHOLE QUESTION OF PERSONAL FINANCIAL RESPONSIBILITY, HOW DOES THAT FIT IN. AND LAST BUT NOT LEAST IS, I GUESS I WOULD CALL IT SILO DESTRUCTION. WE ARE ALL GRAPPLING WITH THAT IN THE SOCIAL SERVICES FIELD IN THE WAY THE GOVERNMENT HAS SET THESE THINGS UP OVER THE YEARS THERE ARE CHALLENGED TO SILO DESTRUCTION, YOU DESTROY SOMETHING, SOMEBODY GETS HURT, HOW DO YOU BALANCE ALL OF THIS? IT'S LIKE THE PILLOW PHILOSOPHY, IF YOU HIT HERE WHAT COMES UP THERE. I AM NOT SAYING WE SHOULDN'T ASK FOR THAT, I AM ALL FOR FOR IT, BUT WE HAVE CONSEQUENCES TO WORK THROUGH. I LIKE THE CONCEPT OF RETHINKING MEDICARE MEDICAID, THAT WOULD BE DYNAMITE I APPRECIATE YOU DIDN'T WANT TO USE THOSE PARTICULAR WORDS, MAYBE THE CONFERENCE CAN'T DO ANYTHING. REMEMBER, AS FAR AS CONFERENCE IS CONCERNED, THIS IS A START FOR A LOT OF THESE ISSUES AND AN OPPORTUNITY TO PULL THINGS TOGETHER TO EDUCATE A LOT OF PEOPLE WHO WILL BE THERE WHO WOULDN'T BE REAL EXCELLENT PARTICIPANTS IN THIS ROOM. SO, WE HAVE GOT A LOT OF ISSUES TO COVER, WE HAVE GOT TO GET INTEREST THROUGHOUT THE CONFERENCE. I EXPECT THAT WILL GO FORWARD. I ALSO NOTICE THAT MY COLLEAGUE, BOB, IS STILL HERE HANGING IN HERE AND A TERRIFIC MEMBER OF THE POLICY COMMITTEE AND THE OTHER MEMBERS OF THE ADVISORY COMMITTEE ARE

HERE THEY HAVE BEEN LISTENING, YOU HAVE GOT A LOT OF SUPPORTERS. TWO OTHER THINGS TO CLOSE ON, WE DO HAVE A FEW OTHER THINGS, AS I KEEP SAYING THE WHITE HOUSE CONFERENCE IS TRYING TO ACCOMPLISH, AND ONE OF THEM HAS TO DO WITH FITNESS AND THE OTHER ONE HAS TO DO WITH TECHNOLOGY.

I DIDN'T MENTION THESE YESTERDAY, BUT ON THE SUBJECT OF FITNESS, WE ARE TRYING TO MAKE FITNESS AND HEALTH AN IMPORTANT FOCUS. KIND OF A OVER ARCHING THEME OF THIS CONFERENCE. SO THAT WE GET PEOPLE TO FOCUS ON THEIR RESPONSIBILITY TO THE BEST OF THEIR ABILITY FOR THEIR INDIVIDUAL HEALTH. AND WE ALL KNOW THAT BEING PHYSICALLY FIT TO THE BEST OF OUR ABILITY IS REALLY IMPORTANT TO ALL OF US. SO, WE ARE STRENGTH -- WE ARE PUTTING TOGETHER A HEALTHY FITNESS FOCUS ON THE FIRST DAY OF THE CONFERENCE THAT WE EXPECT WILL HAVE A LOT OF ENERGY TO IT. AND WE EXPECT ALSO THAT WE WILL BE ASKING DELEGATES TO STEP UP TO THE PLATE, IF THEY WOULD LIKE TO. I WILL BE ENCOURAGING THEM. THE WHITE HOUSE CONFERENCE ON AGING, THE PRESIDENT'S CHALLENGE ON PHYSICAL FITNESS, SOME OF THIS YOU ALL MAY HAVE HEARD ABOUT THE CHALLENGE, BUT BASICALLY IT'S TO CHALLENGE EACH DELEGATE TO UNDERTAKE SOME MINI, MAXI DAILY ACTIVITY OF THEIR CHOICE, AS LONG AS IT'S SOME KIND OF EXERCISE AT LEAST 6 WEEKS BEFORE THE CONFERENCE, FIVE DAYS A WEEK, AND TO HAVE A MODEST FITNESS GOAL FOR EVERYBODY WHO IS A DELEGATE SO THAT THEY CAN -- WE ARE NOT EXPECTING THEM TO CLIMB A MOUNTAIN, BUT WE ARE SAYING -- OR DO A TRIATHOLON -- CAN YOU COME TO THE CONFERENCE TO THE BEST OF YOUR ABILITY, HEALTHY, FIT PHYSICALLY AND MENTALLY. AND SO THAT YOU, AS A DELEGATE, CAN BE A MODEL AS YOU GO HOME OR GO WHEREVER YOU CAME FROM. TO KIND OF SPREAD THE WORD. THIS IS REALLY IMPORTANT TO ALL OF US. SO -- AND IT WILL BE WINTER, SO I AM NOT GOING TO PUT ANYBODY OUT IN THE SNOW, BUT I THINK WE WILL HAVE OPPORTUNITIES AS WELL AS WE HOPE THOUGHTFUL. THEN FOLLOWING ON WHAT ASSISTANT TO THE PRESIDENT CLAUDE ALLEN TALKED ABOUT YESTERDAY IS THE WHOLE USE OF TECHNOLOGY. WE HAVE -- WE WILL HAVE THE FIRST EVER TECHNOLOGY PAVILION AT THE CONFERENCE, WHICH WILL BE OPEN TO MORE THAN CONFERREES, AND IT WILL SHOW CASE EMERGING PRODUCTS AND IDEAS THAT BETTER THE LIVES OF OLDER PERSONS OF ALL OF US. WE EXPECT TO HAVE A LOT OF SUPPORT FROM THE PRIVATE SECTOR, IF YOU HAVE IDEAS IN THAT AREA OR YOU KNOW COMPANIES THAT WE SHOULD BE INVITING, TO BE PART OF THE TECHNOLOGY PAVILION, WORKING WITH CAST UNDER THE CENTER FOR ASSISTIVE SERVICES AND TECHNOLOGIES UMBRELLA, I THINK THAT

WILL BE EXCITING. WE HAVE FOLKS COMING FROM SILICON VALLEY AND ALL SORTS OF PLACES, IF THERE IS SOMETHING YOU WANT TO TELL US ABOUT, WE ARE VERY WILLING TO LISTEN. SO, WITH THAT, WE LOOK FORWARD TO CONTINUING TO HEAR FROM YOU. WE LOOK FORWARD TO THE WORK THAT YOU ARE GOING TO PULL TOGETHER. AND WE THINK THAT THE POLICY COMMITTEE WILL BE VERY PLEASED WITH WHAT YOU FINALLY PUT TOGETHER, AND THE REPORT THAT YOU PROVIDE US. WE THINK YOU ADDRESSED A LOT OF TOUGH ISSUES, NOTHING IS EASY. AND YOU HAVE DONE TOUGH SWEATING, ALL I CAN SAY IS THANK YOU, WITH THAT I HAVE FORMALLY CONCLUDED AND ADJOURN THIS WHITE HOUSE CONFERENCE ON AGING MINI CONFERENCE.

(APPLAUSE)

(CONFERENCE CONCLUDES.)